

When Resistance Meets Law and Policy:
Disabled People and the Independent
Living Counter-Narrative in Wales

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This thesis is submitted in partial fulfilment of the requirements
for the degree of Doctor of Philosophy.

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This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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This thesis is dedicated to my father,
whose dearest wish was to see it completed.

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Abstract

This thesis studies independent living as a counter-narrative of identity reconstruction devised by the disabled people's movement to resist dominant social narratives of otherness, deficit, dependency and 'care'. In particular it examines what happens to that counter-narrative when disabled activists have attempted to insert it into policy and law. It considers whether the counter-narrative can remain intact in this context and the implications – for disabled people and the counter-narrative itself – of the model that is constructed in the policy and legislative context. The policy field selected for the study is adult social care in Wales, where there are emergent governance institutions and an expectation of third sector involvement in policy development.

Using texts from the disabled people's movement as data, the study identifies how independent living functions as a counter-narrative and whether there are distinctions between the model constructed by the disabled people's movement in the UK as a whole, and by the movement in Wales. Core fragments of the counter-narrative are identified and traced through into Welsh Government policy and legal texts. An analytical framework of narrative relationships of 'adjacency' and 'collision' is developed to examine these fragments and establish their use in the policy and legislative contexts.

The study finds that while the attempted incorporation of independent living into Welsh adult social care policy has been partially successful, it has not yet succeeded in overturning master narratives that enable and perpetuate the structural and internalised oppression of disabled people. Both colliding and adjacent ideas were intentionally and unintentionally neutralised in policy and legislation, allowing master narratives to thrive. This was a result of multiple factors, including the collision at a fundamental level of certain core fragments of independent living and the principles of Welsh Government public sector policy, misunderstandings, the loss of the element of resistance and the financial context of austerity, which is undermining not only the ability of the Welsh Government to respond to grassroots demands, but the Welsh Government's own public sector values. However, the study finds that if these problems can be tackled, there is scope for independent living to feature effectively in Welsh policy and for distinct approaches to it to be developed.

List of Abbreviations

ADL	Anti-Discrimination Legislation
BCODP	The British Council of Organisations of Disabled People
CIL	Centre for Independent Living
DAN	Direct Action Network
DCDP	Derbyshire Coalition of Disabled People
DCIL	Derbyshire Centre for Integrated Living
DRC	Disability Rights Commission
DPM	Disabled people's Movement
DPO	Disabled people's organisation
EHRC	Equality and Human Rights Commission
ENIL	European Network on Independent Living
HCIL	Hampshire Centre for Independent Living
ILF	Independent Living Fund
NCIL	National Centre for Independent Living
ROFA	Reclaiming Our Futures Alliance
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UPIAS	The Union of the Physically Impaired Against Segregation
WCVA	Wales Council for Voluntary Action
WAG	Welsh Assembly Government
WG	Welsh Government
VSPC	Voluntary Sector Partnership Council

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Part I: Background and Contexts

Chapter 1: Introduction

1. Introduction: Independent living

This thesis explores independent living as a counter-narrative of resistance and identity reconstruction developed by the disabled people's movement. It examines what has happened to that counter-narrative when disabled activists have sought to insert it into government policy and legislation in Wales. The purpose of the thesis is to understand the impact of this incorporation on the construction of independent living and the implications for disabled people and others who campaign to have their ideas translated into policy commitments.

Independent living is a philosophy developed by the disabled people's movement as a response to experiences of institutionalisation and exclusion. Its core principle is the right of disabled people to have the same opportunities as their non-disabled peers – to be in control of their own lives, to pursue their own work and social ambitions, and to live in the place and with the people of one's choice – in short, to have the kind of life that, generally speaking, non-disabled people take for granted. In the words of John Evans, one of the pioneers of independent living in the UK, independent living is:

the ability to decide and choose what a person wants, where to live and how, what to do, and how to set about doing it.... the freedom to participate fully in the community.... It is also the taking and establishment of self-control and self-determination in the total management of a person's everyday life and affairs. It is about ensuring that all disabled people have the equality of opportunity in the chances and choices of life like everybody else.¹

¹ John Evans, 'Independent Living and Centres for Independent Living as an Alternative to Institutions' (presentation, Brussels, 9 June 2001) <<http://disability-studies.leeds.ac.uk/files/library/evans-Centres-Independent-Living-Alternative-Institutions.pdf>> accessed 19 July 2019, 1-2.

In this thesis, the focus is on independent living in Wales. However, independent living is a global phenomenon. From around the 1970s, disabled activists and their allies have campaigned for independent living across the world, with the early battles taking place particularly in the US, the UK, the Nordic states and western Europe.² International independent living activist and support networks and conferences have given rise to shared statements of principles.³ Independent living is now incorporated into the UN Convention on the Rights of Persons with Disabilities (UNCRPD), adopted by the UN in 2006 and ratified by the UK in 2009. As a whole, the UNCRPD is a statement of equal rights and equal opportunities for all disabled people.⁴ Of particular importance, however, is Article 19, which creates a legal right for disabled people to live independently in the community, with choices and access equal to others.⁵ Signatory states are required to progressively realise the rights expressed in the UNCRPD, and Article 4(3) of the Convention requires states parties to ‘closely consult with and actively involve’ representative organisations of disabled people in the development of policy and legislation intended to implement it. In this context the findings of this thesis have a significance well beyond Wales and the UK.

2. The origin and purpose of this thesis

I became aware of independent living through work undertaken for an MSc project. This explored the idea of ‘independence’ in Westminster adult social care policy documents, which I had identified as a site of contested meaning. Certain of these texts referred to independent living as a matter in its own right, which had a distinct content from the idea of ‘independence’ as it is typically understood and which had been devised by the grassroots disabled people’s movement. The impetus for this

² See Chapter 2, section 4.

³ For example, the Strasbourg Resolutions. European Network on Independent Living, ‘The Strasbourg Resolutions’ (1989) (*Independent Living Institute*, undated) <<https://www.independentliving.org/docs2/enilstrasbourgresolutions.html>> accessed 14 May 2018; and the ‘Tenerife Declaration’, developed and signed at the first European Congress on Independent Living in April 2003 (*Independent Living Institute*, undated) <<https://www.independentliving.org/docs6/tenrife20020426en.html>> accessed 10 July 2019.

⁴ This is the first articulation of a right connected with independent living in international law. Arlene Kanter, *The Development of Disability Rights under International Law: From Charity to Human Rights* (Routledge 2015) ch 2.

⁵ The UNCRPD is discussed in Chapter 2, section 4 and Chapter 6, section 5.

thesis originated in that MSc project. It became clear that in Westminster, independent living had gained significant traction. Indeed, at one stage it had been the core focus of disability policy that was explicitly devised in close contact with disabled people.⁶ Both this inclusion of disabled people in policy development, and the centrality of independent living were a huge success for the disabled people's movement and held the potential permanently to shift the basis of disability policy. However, when I read recent texts written by disabled activists, it was clear that despite these policy successes and the existence of the UNCRPD, the practical attainment of independent living and the impact of independent living on individual lives was not being experienced. In many cases activists were talking of failures of the realisation of independent living, and even of the co-optation and colonisation of independent living and other ideas of the disabled people's movement.⁷

It was clear that a number of things had occurred. There were certainly problems of implementation and a lack of commitment to or realisation of policy promises. Some of this was at least partly due to the austerity context. Disabled activists and others had examined the implementation of policy, assessing the practical experiences of disabled people against the standards of independent living.⁸ However, there also appeared to be a lack of *understanding* of the idea of independent living in policy. It seemed that an apparent consensus on certain elements of independent living might be masking important differences of interpretation. How this had happened was not

⁶ Prime Minister's Strategy Unit and others, 'Improving the Life Chances of Disabled People' (TSO 2005); and Office for Disability Issues, 'Independent Living: A Cross-Government Strategy about Independent Living for Disabled People' (HM Government, 2008).

⁷ Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011); Michael Oliver, 'Welfare and the Wisdom of the Past' (*Disability Now*, February 2013) <<http://www.disabilitynow.org.uk/article/welfare-and-wisdom-past>> accessed 19 August 2013.

⁸ For example, Jenny Morris, 'Independent Living Strategy: A Review of Progress' (In Control and Disability Rights UK 2014) <<https://www.disabilityrightsuk.org/sites/default/files/pdf/IndependentLivingStrategy-A%20review%20of%20progress.pdf>> accessed 19 July 2019; Inclusion London, 'Evidence of Breaches of Disabled People's Rights under the UN Convention on the Rights of Persons with Disabilities' (2015) <<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/equality-and-human-rights/evidence-of-breaches-of-disabled-peoples-rights-under-the-un-convention-on-the-rights-of-persons-with-disabilities/>> accessed 2 January 2017; In Control, 'Independent Living Survey 2016' (In Control on behalf of the Independent Living Strategy Group, 2016) <<http://www.in-control.org.uk/media/243039/independent%20living%20survey%202016%20v2.pdf>> accessed 19 July 2019; Merton Centre for Independent Living, 'Choice Control and Independent Living: Putting the Care Act into Practice' (2018) <<https://www.mertoncil.org.uk/assets/documents/choice-control-and-independen>> accessed 19 July 2019.

obvious and there was limited study of how independent living had been *constructed* in policy and what its intended or unintended meanings were in that context. It therefore seemed to me to be necessary to understand how independent living has been formed, developed and deployed in policy documents. This PhD project provided the opportunity to study that aspect. Using naturally occurring written documents as data, I examine how independent living is constructed in texts emerging from the disabled people's movement in the UK and Wales, and how it is constructed in government policy and legislative texts in the Welsh context. The aim is to establish how independent living materialises in these different groups of texts, and the implications of these materialisations for independent living and disabled people.

In personal terms, the thesis provided the opportunity to explore independent living itself. Independent living struck me as a powerful account of the human condition, and what it means to have one's life restricted by social responses to bodies and minds that are socially constructed as unusual, difficult or 'wrong'. As a previously non-disabled person,⁹ albeit one who had grown up with and around disabled people, independent living brought a new insight into the denials of equality and opportunity that arise from responses to differences in physical, cognitive or communication functioning. I was deeply intrigued by the fact that although I had formerly been employed by two large disability-related charities, I had not explicitly become aware of independent living, although I knew of the existence of activist organisations of disabled people. The project provided an opportunity to explore the fundamental distinction between these different groups in how disability was constructed and understood.

⁹ At the outset of this project I identified as non-disabled. This is no longer the case. In 2015 I developed severe tinnitus and in 2017 I rapidly lost all hearing in one ear. The conditions are permanent and irreversible. As no residual hearing remains in that ear, a hearing aid is of limited use, although a CROS aid, which transfers sound from the 'dead' ear to the other is of some value.

3. The theoretical framework

To undertake this study I have deployed – and developed – the theoretical framework of counter-narrative analysis. Counter-narratives¹⁰ are ‘stories’, typically developed by marginalised or less powerful groups or individuals, which question or challenge ‘master narratives’ – accounts or understandings devised and perpetuated by dominant groups. Master narratives delineate acceptable ways of performing social roles,¹¹ and are so much a part of social understandings that they come to form a culture’s generally accepted sense of what is ‘normal’ or ‘natural’. They establish certain identities for particular social groups and demand particular forms of behaviour from those groups and individuals within them. As individuals and group members, we learn what is expected of us from these master narratives, and they form our understandings of ourselves and others. The purpose of a counter-narrative is to devise and promote new ways of being that resist these constructed identities and legitimate the experiences of the ‘outgroup’. The development of a counter-narrative enables the outgroup to create a new identity, forged on its own principles, and resist master narratives that restrict and deny the experiences and capabilities of the group. Nelson describes this as the ‘repair’ of damaged identities.¹²

The concept of counter-narrative was a natural fit for independent living. It chimed with the experiences of a group that has expressed a collective experience and history of marginalisation, exclusion, domination and oppression, and which has articulated a problem of internalised identity damage through the absorption of social messages that have created particular roles and personalities for disabled people. It also resonated with the fact that disabled activists in the UK have long understood that challenging their social exclusion and material circumstances would require a shift in the way society constructs and understands disability. This is now reflected in

¹⁰ Some authors use the term ‘counterstory’. In this thesis, the term ‘counter-narrative’ is used, which is the more widely used phrase. In critical race theory, the term ‘counter-story’ is more commonly used.

¹¹ Molly Andrews, ‘Introduction: Counter-Narratives and the Power to Oppose’ (2002) 12(1) *Narrative Inquiry* 1; Michael Bamberg, ‘Considering Counter Narratives’ in Michael Bamberg and Molly Andrews (eds), *Considering Counter-Narratives: Narrating, Resisting, Making Sense* (John Benjamins Publishing 2004).

¹² Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Cornell University Press 2001).

the UNCRPD. A core purpose of the Convention is to change the way disabled people are perceived, and to create a new legal identity of citizenship and rights-holders for those previously considered to be objects of charity.¹³ Counter-narrative theory gave scope to examine independent living as an intentionally created narrative of resistance to the experiences and construction of disabled people in the UK, and provided a frame for the analysis of whether and how that narrative was treated and constructed in policy texts.

4. A case study of independent living in adult social care policy in Wales

This thesis both examines and explores independent living as a counter-narrative *and* acts as a broader case study of the impact on a counter-narrative of absorption into policy and legislation. The particular case study examined is that of independent living in adult social care policy and legislation in the Welsh context.

‘Social care’ is the term typically used to refer to the support provided by local authorities to people who need assistance with daily activities, such as getting up and getting dressed, cooking and eating, parenting or getting around. In the UK social care is distinct from health care, underpinned by largely separate legislation and delivery structures from those that govern the National Health Service. The policy area of adult social care was selected for study partly because of the heritage of the project, but essentially because of the particular connection between social care and independent living. For independent living to be achieved, adjustments are required in multiple areas that are typically considered separately in policy development. There must, for example, be accessible housing and transport, an accessible environment, and full and equal employment and education opportunities for disabled and non-disabled people.¹⁴ However, social care is pivotal for two reasons. Firstly, independent living arose as specific resistance to certain forms of

¹³ See Chapter 2, section 4.

¹⁴ The disabled people’s movement has identified 12 ‘pillars’ of independent living, which are set out in Chapter 2, section 4.

social 'care' provision, particularly institutionalisation,¹⁵ creating a historical connection. Secondly, for disabled people who need support in daily living, how social care is provided is fundamental for the self-determination and ability to live the meaningful life that Evans describes.¹⁶ Many disabled activists choose to refer to 'independent living support' rather than 'social care' to express the assistance they need in daily life.¹⁷ Morris has argued that a 'political and ideological battle is being waged' around how people receive assistance, with policy makers thinking in terms of 'community care' and disabled people in terms of independent living.¹⁸ A final point of interest was that legislation on adult social care had recently been revised in both Wales and England, which had created an opportunity for a right to independent living to be enshrined in domestic statute.¹⁹

The Welsh policy context was selected for this project for many reasons. Firstly, the bulk of activist and academic literature examining both independent living and social care policy pertained to the Westminster context, with a void existing in relation to Wales.²⁰ The dominant political principles in Wales are distinct from those in Westminster, and this would have particular implications for how independent living might be incorporated into policy.²¹ Secondly, prior to the start of this project, the Welsh Government had produced its first pan-disability and cross-governmental policy document, the *Framework for Action on Independent Living*,²² developed in

¹⁵ This is explained and explored in Chapters 2 and 6.

¹⁶ Jane Campbell, 'Social Care as an Equality and Human Rights Issue' (speech at Institute of Public Policy Research, 19 February 2008) (*Equality and Human Rights Commission*, last updated 14 April 2016) <<https://www.equalityhumanrights.com/en/care-and-support/speech-social-care-equality-and-human-rights-issue>> accessed 19 July 2019.

¹⁷ For example, Reclaiming Our Futures Alliance, 'Independent Living for the Future - Our Vision for a National Independent Living Support System' (April 2019) <<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/independent-living-social-care-and-health/national-independent-living-strategy/>> accessed 18 June 2019.

¹⁸ Jenny Morris, *Independent Lives? Community Care and Disabled People* (Palgrave Macmillan 1993), ix.

¹⁹ See Chapter 3, section 6. See Chapter 2, section 4 for discussion of attempts to bring a right to independent living into domestic legislation.

²⁰ Social care has been devolved to Wales since 1999. The National Assembly for Wales was created by the Government of Wales Act 1998 and the first Assembly Members elected in 1999. Initially the Assembly had limited powers to make secondary legislation only in various fields including social services. For a summary of the history of devolution and its relevance to social care policy and legislation, see Chapter 3.

²¹ See Chapter 3, section 5.

²² Welsh Government, 'Framework for Action on Independent Living' (2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018.

close consultation with disabled people's organisations and the third sector. As its name indicates, the purpose of this document was to establish a Welsh policy explicitly to enable independent living. There was therefore the opportunity to study independent living in recent policy that was produced with disabled activists, nearly a decade after independent living had first entered the UK policy consciousness. Finally, and most importantly, one of the stated reasons for Welsh devolution was the creation of a governance structure in which the public had greater participation in the policy process. Statutory duties were created not only to enable this participation, but also to prioritise equality. These matters are set out in full in Chapter 3. Examining independent living in Wales therefore gave scope to consider the impact on a counter-narrative of its translation into policy in a context in which there is a specific and explicit requirement on both the Welsh Government and the National Assembly for Wales to consult civil society organisations in policy development.

It should be noted that where Welsh documents were bilingual – whether those of the disabled people's movement or policy and legislative documents – only the English documents (or English sections) were studied. Study of the Welsh documents or sections could not be undertaken as I am not a Welsh speaker and the close study of texts requires fluency in the relevant language. Interrogation of the Welsh element of bilingual texts would have required the employment of a Welsh speaker, which was not resourced under the terms of the research. When sourcing the documents for study from the disabled people's movement, none were found that existed only in Welsh and no movement that operated exclusively in Welsh was encountered. However, it was not possible to explore this exhaustively as this would also have required competence in Welsh.

5. The research questions and an outline of the thesis

The core purpose of this project was to develop an understanding of independent living as a counter-narrative and assess the impact on the construction of that counter-narrative when it becomes enmeshed with the process of policy development. The research question that guided this work was:

- What happens to the activist counter-narrative of independent living when it is incorporated into Welsh Government policy and law on disability and adult social care?

During the project, it became clear that the study of independent living in the Welsh context raised a particular set of questions relating to the interaction between individualised and communitarian approaches to public sector provision. In the English context, core elements of the counter-narrative of independent living have dovetailed with certain public sector policy principles that emphasise individualism, personal responsibility and the privatisation and marketisation of social care.²³ This has been broadly discussed in academic literature and by the disabled people's movement.²⁴ In Wales, where principles of collectivism and universalism underpin the public sector,²⁵ there was a tension between these aspects and the Welsh Government's broad public sector policy principles. This critical tension became a particular focus of the project and the analysis. A second, and secondary, research question was developed to enable the study of this aspect. This research question was:

- How has the Welsh Government's inclination towards communitarian approaches in public sector policy impacted on the construction and incorporation of independent living in disability and adult social care policy and law in Wales?

The thesis is divided into three parts. The first part provides the background and context that is necessary to understand a study of independent living as a counter-narrative in the Welsh policy context. Chapter 2 outlines the history of the disabled people's movement and independent living and Chapter 3 introduces the Welsh policy environment. Chapter 4 sets out the theoretical framework, establishes independent living as a counter-narrative and introduces the theoretical tools for the analysis. In particular, this chapter introduces an analytical framework of 'adjacency and collision' between the counter-narrative and policy principles, devised during this

²³ See Chapter 3, sections 5 and 6.1.

²⁴ See Chapter 6, particularly section 4.4.

²⁵ See Chapter 3, section 5.

project to enable the study of counter-narratives in the policy context. Chapter 5 explains the methods used in the study.

The second part of the thesis examines independent living as a counter-narrative, using texts from the disabled people's movement as data. Chapter 6 identifies both the master narratives that independent living was developed to counter and certain core 'fragments' of the counter-narrative in texts from the UK disabled people's movement. It establishes how independent living does the work of identity reconstruction. Chapter 7 examines these fragments in documents authored by the disabled people's movement in Wales to establish whether a distinctive model of independent living has been constructed by activists in the Welsh context. Chapter 8 draws on the findings of this part of the study to highlight potential areas of adjacency and collision between independent living and Welsh Government policy principles.

The final part of the thesis examines Welsh policy and legislative documents to establish whether and how the counter-narrative of independent living has been incorporated into policy and the impact upon it of that incorporation. Chapter 9 examines the incorporation of fragments of independent living into Welsh Government policy on disability and adult social care prior to the development of the *Framework for Action on Independent Living*, and Chapter 10 provides an analysis of the *Framework*. Chapter 11 examines provisions in the Social Services and Well-being (Wales) Act 2014 to establish how independent living and the identified component fragments are treated in the statutory context. The final chapter considers the implications of the findings in relation to counter-narrative theory, independent living, and disabled people in Wales.

The project makes a contribution on a number of levels and in various areas. In the theoretical field, it clarifies certain aspects of counter-narrative theory and creates an analytical framework to enable the study of a counter-narrative in the policy context. The analysis of independent living as a counter-narrative of resistance and narrative repair gives new insights into how independent living operates and what it achieves in terms of identity reconstruction for disabled people; and the examination of documents from the Welsh as well as the broader UK disabled people's movement

has revealed distinctions between the models of independent living crafted by disabled activists in these two contexts. The final part of the thesis takes the study of counter-narratives into new areas. It demonstrates both the impact on the construction of independent living of its incorporation into policy and legislation in Wales, and how this impact has occurred. The findings from the thesis have implications for the use of counter-narrative theory, for disabled people in Wales, the UK and beyond, and for others seeking to insert activist ideas into policy and legislation.

6. Terminology

Terminology is of critical importance to the disabled people's movement. In this thesis, the terminology chosen by the UK disabled people's movement is used: the term 'disabled people' is used in preference to 'people with disabilities'; and 'impairment' is used to describe a distinction in functioning. These terms reflect the social model of disability, which holds that disability arises from social failures to adjust to impairments. The social model is explained in Chapter 2.

'Care' is also a loaded word for disabled people and the disabled people's movement, which typically prefers the terms 'support' or 'assistance'.²⁶ In this thesis 'social care' is used to refer to the broad policy area set out above, on the basis that this is the phrase used in the policy itself and by many disabled activists when discussing that policy. In the broader text, the terms 'support' or 'assistance' are used unless the discussion relates to the use of the terms 'care' or 'services' in a particular document.

²⁶ See Chapter 6, sections 2 and 4.4.

Chapter 2: Contexts – The disabled people’s movement and independent living in the UK

1. Introduction

This chapter is the first of two which provide the context that is necessary to understand an analysis of independent living in the Welsh context. It provides background information on the disabled people’s movement and independent living. It begins by briefly setting out the history of the disabled people’s movement in the UK. It then outlines the social model of disability, which is the foundation upon which independent living was built and from which it derives much of its meaning. The chapter then provides an overview of the development of independent living in the UK and concludes by establishing the connection between independent living and the social model.

2. The disabled people’s movement in the UK

The history of the UK movement has been chronicled elsewhere and does not need to be re-examined here in detail.¹ This section sets out a brief summary.

In this thesis the disabled people’s movement refers to the self-identified formal and informal network of individuals and organisations of disabled people which have

¹ Texts by individuals within the movement include: Jane Campbell and Michael Oliver, *Disability Politics: Understanding Our Past, Changing Our Future* (Routledge 1996); Michael Oliver and Colin Barnes, *Disabled People and Social Policy: From Exclusion to Inclusion* (Longman 1998); Ken Davis and Audrey Mullender, *Ten Turbulent Years: A Review of the Work of the Derbyshire Coalition of Disabled People* (University of Nottingham, 1993) available at <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DavisK-TEN-TURBULENT-YEARS.pdf>> accessed 29 September 2018. For a summary and critique of the early movement, see Tom Shakespeare, *Disability Rights and Wrongs Revisited* (2nd edn, Routledge 2014), particularly at 13-17.

been lobbying on a variety of issues since the late 1960s.² If any particular action can be identified as the birth of the movement, it is commonly considered to be the foundation of the organisation the Union of the Physically Impaired Against Segregation (UPIAS)³ following the publication in *The Guardian* of a letter by the disabled activist Paul Hunt calling for disabled people to form their own 'consumer' group.⁴ A number of organisations of disabled people had existed before this, some for decades,⁵ certain of which had engaged in significant political lobbying and activity.⁶ UPIAS, however, developed a new and radical approach to disability and policy which is credited with establishing the movement as we see it today.

The distinctive feature of UPIAS was its questioning not of specific issues impacting on disabled people – such as, for example, a lack of income or rehabilitation – but fundamental beliefs about disability and its social construction.⁷ Guided by activists such as Paul Hunt, who had for some time been drawing similarities between disabled people and other minorities, and Vic Finkelstein, a political exile and former political prisoner from apartheid South Africa,⁸ UPIAS located disability in *social*

² Campbell and Oliver (n1). Morris uses the term to refer specifically to the existence and networking of organisations of disabled people. Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011), available at <<http://www.jrf.org.uk/sites/files/jrf/disability-policy-equality-summary.pdf>> accessed 1 June 2015.

³ Grue suggests that the 'origo' of the disability movement in Britain is the publication of the UPIAS 'manifesto' (or policy statement), Jan Grue, *Disability and Discourse Analysis* (Ashgate 2015), 36. Shakespeare also states that UPIAS has been retrospectively 'celebrated as the inspiration for the British disability movement'. Shakespeare, 'Rights and Wrongs' (n1), 17. Campbell and Oliver are not so specific, attributing the rise of the movement to multiple events and groups but discuss the importance of UPIAS and its work. Campbell and Oliver (n1), particularly chapter 4.

⁴ Paul Hunt, 'Letter to *The Guardian*' *The Guardian* (London, 20 September 1972). Paul Hunt was for some time a resident of the Leonard Cheshire Le Court residential home in Hampshire. He was active in challenging conditions at Le Court and in 1966 brought together and published a series of essays by disabled people. Paul Hunt (ed), *Stigma* (Geoffrey Chapman 1966). For these reasons, Campbell and Oliver state that the work of Paul Hunt, in particular, was 'pivotal to the emergence of the disability movement'. Campbell and Oliver, (n1), 64.

⁵ Oliver and Barnes, *Disabled People and Social Policy* (n1), particularly at 74-75. Some earlier organisations were the National League of the Blind and the Disabled Incomes Group There were also mental health user/survivor movements such as the Alleged Lunatics' Friend Society. N Hervey, 'Advocacy or Folly: The Alleged Lunatics' Friend Society, 1845-6' (1986) 30 *Medical Science* 245.

⁶ People with visual impairments, organised by the National League of the Blind (later the National League of the Blind and Disabled), marched against poor working conditions as early as 1920 (Oliver and Barnes, *Disabled People and Social Policy* (n1) 74) and in the 1960s the Disabled Income Group became 'one of the largest mass organisations of disabled people in the world'. Vic Finkelstein, 'A Personal Journey into Disability Politics' (presentation, 7 February 2001) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-presentn.pdf>> accessed 7 March 2019, 3.

⁷ Finkelstein indicates that the early membership of UPIAS spent two to three years in discussion on relevant issues. Finkelstein 'Personal Journey' (n6), 5.

⁸ Ibid.

responses to physical impairments⁹ rather than the impairment itself. They argued that in this form, disability amounted to direct oppression – a ‘power relationship of control’.¹⁰ This enabled disabled people to express their experiences in terms of discrimination rather than need, and solutions in terms of equality rather than ‘care’.¹¹ The views, actions and construction of UPIAS have been subject to criticism,¹² but there can be no doubt that these developments rendered UPIAS distinct from organisations of disabled people that had gone before and created a new and theoretical basis for collective action.

The movement has always made a distinction between disabled people’s organisations (DPOs),¹³ which are formed of and controlled by disabled people,¹⁴

⁹ Initially the movement was formed of and focused on individuals with physical impairment, although today it also embraces people with cognitive impairments, the neurodiverse community and people with mental health conditions (or survivors of psychiatric intervention).

¹⁰ Judy Hunt, ‘A Revolutionary Group with a Revolutionary Message’ (text of a talk reproduced in Coalition, 2001) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Hunt-J-a-revolutionary-group-with-a-revolutionary-message.pdf>> accessed 7 March 2019. See also: UPIAS, ‘Policy Statement’ (1974, amended 1976) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-UPIAS.pdf>> accessed 20 October 2014; UPIAS, ‘Fundamental Principles of Disability’ (1975) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf>> accessed 20 October 2014; Vic Finkelstein, ‘Attitudes and Disabled People: Issues for Discussion’ (World Rehabilitation Fund 1980) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-attitudes.pdf>> accessed 7 March 2019.

¹¹ Ken Davis, ‘The Disabled People’s Movement: Putting the Power in Empowerment’ (paper for seminar at Sheffield University 1996, updated 1998) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DavisK-davis-empowerment.pdf>> accessed 12 July 2019. Davis notes that organisations of disabled people that existed prior to UPIAS sought improvements ‘very much in the prevailing welfarist mode’ while UPIAS ‘paved the way for a civil rights struggle when it redefined disability’.

¹² Campbell and Oliver set out responses to UPIAS from those both within and outside it, which include comments about rigidity of principle, illiberalism, secrecy, elitism and male dominance, although many reasons for these attributes are also considered. Campbell and Oliver (n1), Chapter 4. For criticisms, see also: Shakespeare, *Rights and Wrongs* (n1), particularly p17.

¹³ In recent years, the term ‘Deaf and Disabled People’s Organisations’ (DDPOs) has increasingly been used to cover both DPOs and organisations run by Deaf people for the Deaf community. ‘User-led organisations’ (ULOs) is a further term for organisations run by disabled people, particularly among survivors of psychiatric services.

¹⁴ A disabled people’s organisation (DPO) is one that is run and controlled by disabled people and typically has a cross-disability focus. Jolly suggests that to be considered a DPO, at least 75 percent of people at decision-making levels must be disabled. Debbie Jolly, ‘Personal Assistance and Independent Living’ (paper prepared for ENIL, undated) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/jolly-Personal-Assistance-and-Independent-Living1.pdf>> accessed 10 November 2016. Inclusion London suggests that either the Board of the organisation must be made up of at least 75 percent disabled people, or that at least 50 percent of the staff of the organisation are disabled people, or both. Inclusion London, ‘DDPO Directory’ (undated) <<https://www.inclusionlondon.org.uk/directory/listing/>> accessed 18 February 2019. The UN Committee on the Rights of Persons with Disabilities states, ‘The Committee considers that organizations of persons with disabilities should be rooted, committed to and fully respect the

and the significantly wider group of organisations – including a number of large national charities – which focus on disability, but which are not predominantly formed of, or established and controlled by, disabled people. The movement identifies as being composed of disabled people and DPOs only,¹⁵ with allies who accept certain principles.¹⁶ Indeed, it arose partly in response to the historical domination of campaigning around disability issues by charities controlled by non-disabled people which the movement has sometimes called the ‘disability establishment’.¹⁷ From the outset of the movement, there has been a strong mistrust of these charities,¹⁸ which have been seen as self-serving and directly oppressive of disabled people.¹⁹ Indeed, many disability charities are historically providers of, and retain financial interests in, the forms of services that disabled activists have rejected.²⁰ Barnes and Mercer summarise various criticisms of non-DPO disability organisations, which include the existence of an ethos that reinforces dependency, the use of ‘personal tragedy’ imagery in fundraising, political inertness and a ‘cosy’ relationship with the state.²¹ Other criticisms from the movement include the failure of ‘establishment’ charities to involve disabled people while purporting to speak on their behalf, their lack of democratic accountability, and their absorption of resources that might otherwise be

principles and rights recognized in the Convention. They can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves.’ UN Committee on the Rights of Persons with Disabilities, ‘General Comment No. 7 on the Participation of Persons with Disabilities, Including Children with Disabilities, through their Representative Organizations, in the Implementation and Monitoring of the Convention’ (UN Doc CRPD/C/GC/7, adopted on 9 November 2018) <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>> accessed 12 July 2019.

¹⁵ Campbell and Oliver (n1) 22.

¹⁶ Generally speaking, these are social model principles (see further below) and other ideas, such as the right of disabled people to be in control of their own lives and organisations, and the expertise of disabled people in their own circumstances. This was a feature of the movement from the outset, with UPIAS, in particular, talking about the ‘correct’ view of disability. UPIAS, ‘Fundamental Principles’ (n10). The UNCRPD has more recently set out a statement as to what constitutes an ‘ally’ of DPOs. See main text of this chapter, Section 4.

¹⁷ Campbell and Oliver, (n1).

¹⁸ UPIAS, ‘Fundamental Principles’ (n10); Campbell and Oliver, (n1).

¹⁹ Campbell and Oliver, (n1). Oliver has been a particularly vocal proponent of this view. See, John Pring, ‘Oliver Comes out of Retirement to Deliver Stinging Rebuke to ‘Parasite’ Charities’ (*Disability News Service*, 30 November 2017) <<https://www.disabilitynewsservice.com/oliver-comes-out-of-retirement-to-deliver-stinging-rebuke-to-parasite-charities/>> accessed 4 March 2019. For a personal experience of direct oppression of an individual by staff of a disability charity, see comments made by Jane Campbell in interview, Campbell and Oliver (n1) ch 10.

²⁰ Campbell and Oliver (n1). Mike Oliver, ‘Isolation, Segregation, Liberation: Remembering Where We Came From’, (*Disability Now*, November 2013) <<http://www.disabilitynow.org.uk/article/isolation-segregation-liberation-remembering-where-we-came>> accessed 27 May 2015 (no longer available online, copy archived by the author).

²¹ Colin Barnes and Geof Mercer, *Independent Futures: Creating User-Led Disability Services in a Disabling Society* (Policy Press 2006), 31.

available to DPOs.²² Morris argues that it is now increasingly difficult to distinguish between ‘organisations “of” and organisations “for” disabled people, as the latter have, in recent years, sought to engage disabled people in their management structures and increasingly associated themselves with the ideas and campaigns of the grassroots movement.²³ However, the UNCRPD implicitly requires a distinction between ‘representative organisations’ of disabled people and others working in the field of disability,²⁴ and the UN Committee recently developed a general comment establishing that a representative organisation is considered to be a DPO, or an ally organisation based on principles of supported decision making and the CRPD.²⁵

In this thesis the disabled people’s movement is considered to be a social movement. It is not the purpose of the thesis to analyse its history and existence in terms of social movement theory, and that discussion exists elsewhere.²⁶ Similarly, the question of how far the movement is representative of disabled people in the UK is outside the scope of this thesis. Barnes and Mercer indicate that ‘it was always a minority of disabled people that accepted a positive or politicised “disabled identity” and became active in the Disabled People’s Movement’;²⁷ and Shakespeare notes both that UPIAS never grew into a popular force and that historically many ‘impairment groups’ were initially either not welcomed into the movement or chose to remain separate.²⁸ The movement now embraces multiple different groups and has become more intersectional in its approach.²⁹ However, as with any grassroots movement, the question of whether the movement can realistically be considered to

²² Campbell and Oliver (n1).

²³ Morris (n2).

²⁴ Article 4(3) of the UNCRPD requires the involvement of disabled people in the development of policy affecting them through their ‘representative organisations’.

²⁵ UN Committee on the Rights of Persons with Disabilities, (n7).

²⁶ See, among others, Campbell and Oliver (n1) particularly ch 9; Mark Priestley, *Disability Politics and Community Care* (Jessica Kingsley 1999), particularly chapter 3; Tom Shakespeare, ‘Disabled People’s Self-Organisation: A New Social Movement?’ (1993) 8(3) *Disability, Handicap & Society* 249; Angharad E Beckett, ‘Understanding Social Movements: Theorizing the Disability Movement in Conditions of Late Modernity’ (2006) 54(4) *The Sociological Review* 734; Susan Peters, Susan Gabel and Simoni Symeonidou, ‘Resistance, Transformation and the Politics of Hope: Imagining a Way Forward for the Disabled People’s Movement’ (2009) 24(5) *Disability & Society* 543.

²⁷ Barnes and Mercer, *Independent Futures* (n21) 35. Barnes and Mercer note that this is typical of most protest movements.

²⁸ Shakespeare, *Rights and Wrongs* (n1) particularly 99-101.

²⁹ Barnes and Mercer, *Independent Futures* (n21) state at 36: ‘Subsequent discussions among disabled people and their organisations have amended the reference to “physical impairments” so that any impairment (including sensory and intellectual examples) falls within the potential scope of disability’.

speak on behalf of the majority of disabled people remains open. In more recent years, as disabled people have become more visible in public life, and social media has enabled greater access to discussion fora, the movement has arguably fragmented from its original small group of organisations that had a relatively consistent message and a strong solidarity.³⁰

A distinction is made in this thesis between what are termed (in the thesis) the ‘Anglo-British disabled people’s movement’ and the ‘Welsh disabled people’s movement’. The first is composed of organisations and individuals who have historically worked across the UK or English and Welsh context but have, since devolution, focused predominantly on developments in England in relation to devolved matters.³¹ The second refers to the groups of organisations and individuals which work primarily in the Welsh context, responding to Welsh developments on devolved matters, but who may also contribute to discussion on UK developments.³² This distinction is not absolute and both groups share the common heritage outlined above. Where both groups are under consideration or no distinction is necessary, the term ‘disabled people’s movement’ or ‘UK disabled people’s movement’ is used. It should be noted that neither the term ‘Anglo-British disabled people’s movement’ nor ‘Welsh disabled people’s movement’ is used within the movement itself. They have

³⁰ In particular, a movement of ‘sick and disabled’ people has developed in the UK, discussed in Section 3 of this chapter. Similarly, the Shaw Trust 2018 ‘Power List’ of ‘Britain’s most influential disabled people’ includes individuals who are activists from the disabled people’s movement (such as Jane Campbell and Kamran Mallik) and individuals who have an activist role but have little connection with the movement or its theoretical background and political activism (such as Martyn Sibley, co-founder of the online ‘Disability Horizons’). The list demonstrates much greater fluidity between influential disabled people who are and who are not intentionally and consciously connected with the movement as it is traditionally understood. It should be noted that the Shaw Trust, which creates the list, is a non-DPO disability charity. The list is available at Shaw Trust, ‘Power 100 2017’ (*Shaw Trust*, undated) <<http://disabilitypower100.com/>> accessed 6 May 2019.

³¹ The Welsh context, including devolution and the form of the Welsh disabled people’s movement is discussed in the following chapter.

³² For example, in the recent developments on legislation in social care in both England and Wales, Disability Rights UK responded to consultation around the Bill that became the Care Act 2014 and Disability Wales responded to consultation around the Bill that became the Social Services and Well-being (Wales) Act 2014. Consultation responses from both groups are included in the datasets of texts from the UK and Welsh disabled people’s movements (see Chapter 5 and Appendix 1). Both groups provided comment and analysis to the UN Committee on the Rights of Persons with Disabilities in its recent inspections of the UK, including by the provision of co-authored documents, for example: Disability Rights UK and Disability Wales, ‘Implementation of the United Nations Convention on the Rights of Persons with Disabilities in England and Wales: Shadow Report’ (January 2017)

<<https://www.disabilityrightsuk.org/sites/default/files/pdf/CRPD%20shadow%20report%20-%20England%20Wales%2026%20January%202017.pdf>> accessed 12 July 2019.

been devised and applied in this thesis as a means of distinguishing between these two groups.³³

3. The social model of disability

In this thesis, the disabled people's movement is identified as a grassroots social movement that is *built upon* resistance in the form of counter-narrative development. Any social movement is, by definition, concerned with the idea and practice of countering. Social movements emerge when individuals come together to pursue specific aspects of social change. However, it is widely recognised that the *defining* feature of the early UK disabled people's movement was challenge to narratives, and particularly narratives of identity. What distinguished UPIAS from previous organisations of disabled people was its conscious attempt to reconceptualise these narratives. This theorising was later developed into the social model of disability, upon which independent living was later constructed.

The social model of disability is now widely discussed. In essence, the model distinguishes disability from physical, cognitive, psychiatric or communication impairments. In 1975, UPIAS argued that:

... it is society which disables physically impaired people. Disability is something *imposed on top of our impairments*, by the way we are unnecessarily isolated and excluded from full participation in society.³⁴

From this basis, the disabled academic Michael Oliver set out two models of disability which he characterised as the 'individual' model – now also commonly

³³ For the origin of the term 'Anglo-British' and discussion of the need to understand the relationships between the different parts of the UK in political discussion, see Ailsa Henderson and others, 'How Brexit was Made in England' (2017) 19(4) *The British Journal of Politics and International Relations* 631.

³⁴ UPIAS, 'Fundamental Principles' (n10), pages unnumbered (emphasis added). Note that even in its earlier policy statement, UPIAS had stated, 'What we are interested in, are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us'. UPIAS, 'Policy Statement' (n10) section 15.

known as the 'medical model' – and the 'social' model. Oliver argued that the medical model conceptualised disability as a series of medical problems, located in individual bodies, which were viewed as a 'personal tragedy' for the individual, and to which the societal answer was treatment and correction.³⁵ In this model the 'problem' of disability is characterised as a *personal* distinction or deficit, and success in overcoming it is measured in terms of how well the individual measures up to a non-disabled 'norm'.³⁶ In contrast, the social model holds that while certain people have individual differences (known as 'impairments'), disability results from the failure of *society* to accept or accommodate those impairments.³⁷ In crude terms, therefore, according to the social model a person is disabled not, for example, by impaired vision, but by the failure of society to respond to that impairment by providing information in Braille, large print, audio or other accessible formats. A central theme of the social model is access, or 'barrier removal' – the dismantling of physical, organisational and attitudinal barriers that prevent disabled people from carrying out activities. When barriers are removed, disabled people are able to participate in society on an equal basis with others.

Both the early disabled people's movement and the early academic discipline of disability studies intentionally applied a Marxist approach and analysis,³⁸ and the social model is characterised by values of collectivism and communitarianism. Oliver argued that the narratives that formed the medical model of disability arose from a society that lauded individualism;³⁹ and the essential feature of the social model is the replacement of a narrative of *individual* deficit with one of *social*, or *community* deficit. As Dodd notes, it requires 'policy responses that address collective needs at a structural level, as well as policies addressing individual needs'.⁴⁰ More

³⁵ Michael Oliver, *Social Work with Disabled People* (Macmillan Press 1983); Michael Oliver, *The Politics of Disablement* (Macmillan 1990) in particular, 43-59.

³⁶ Colin Goble, 'Dependence, Independence and Normality' in John Swain and others (eds), *Disabling Barriers – Enabling Environments* (2nd edn, Sage 2004). Oliver notes that this adjustment was typically assumed to have two aspects – physical and psychological as professionals working in the field assume 'that something happens to the mind as well as to the body', and refutes this suggestion. Oliver 'Social Work' (n35) 16.

³⁷ Oliver, 'Social Work' (n35).

³⁸ Shakespeare, *Rights and Wrongs* (n1) 13-14. In his seminal work on the social model and in disability studies, Oliver drew heavily on Marxist analysis. Oliver, *Politics of Disablement* (n35).

³⁹ Oliver called this a 'core ideology of individualism'. Oliver, *Politics of Disablement* (n35) 46.

⁴⁰ Steven Dodd, 'Personalisation, Individualism and the Politics of Disablement' (2013) 28(2) *Disability & Society* 206, 263. See also Hammarberg, 'From viewing disability as a personal problem that needs

fundamentally, Beckett and Campbell note that it was the social model that enabled disabled people to see each other as members of the same struggle, and produced 'a new "we"'. The disabled people's movement had, and continues to have, a strong focus on and belief in collective action. UPIAS was formed explicitly as a *union* of disabled people with a remit to support other disabled people in collective action, particularly within residential institutions, for 'better conditions, for full control over their personal affairs, and for a democratic say in the management of their Home, Centre or Unit'.⁴¹ Mutual help and peer support were core principles, and it was expected that members would 'take some active part in Union affairs'.⁴²

The social model continues to lie at the heart of the UK disabled people's movement and the movement has been highly effective at inserting it into national and local policy. The Welsh Government formally adopted the social model in 2002,⁴³ and the model has also formed the basis of Westminster policy.⁴⁴ The social model also influenced the development of the UNCRPD, which is discussed in section 4 below.⁴⁵ However, the movement has not yet succeeded in permanently erasing the

to be cured (the medical model), we have come to see the source of the problem: the society's attitude towards persons with disabilities. This means that we have to act collectively as a society in order to remove the barriers that hinder persons with disabilities from living among us and contributing to our society, and to fight against their isolation in institutions or in the back-rooms of family homes'. Thomas Hammarberg, 'Disability Rights: From Charity to Equality' (2011) 6 *European Human Rights Law Review*, 638, 639.

⁴¹ UPIAS, 'Policy Statement' (n10) section 8. Oliver later stated that to UPIAS 'the collective was all'. Campbell and Oliver, (n1) 182. The intense focus on the collective nature of the organisation and its internal collective discipline was problematic for some, including Oliver. Campbell and Oliver, (n1) 66-68 and 182.

⁴² UPIAS, 'Policy Statement' (n10) section 20.

⁴³ Welsh Government, 'Social Model of Disability' (*Welsh Government*, last updated 29 July 2013) <<http://gov.wales/topics/people-and-communities/equality-diversity/rightsequality/disability/socialmodel/?lang=en>> accessed 8 March 2018. The Welsh Government has stated that it was one of the first governments in the world to adopt the social model. Welsh Government, *Framework for Action on Independent Living* (2013)

<<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018, 8. What precisely is meant by 'adopting' the social model is not clear, although it suggests that the principles of the social model should underpin policy that has a particular impact on disabled people (for example, policy on public transport).

⁴⁴ The pivotal 'Life Chances' policy document, which was developed with strong input from disabled activists and DPOs was based on the social model, although it does not use this phrase to describe it. Prime Minister's Strategy Unit and others, 'Improving the Life Chances of Disabled People' (TSO 2005), 8. Prior to this, the legal requirement for reasonable adjustments for disabled people contained in the Disability Discrimination Act 1995 reflects the social model, although the Act itself holds to the medical model of disability in its definition of disability.

⁴⁵ Arlene Kanter, *The Development of Disability Rights under International Law: From Charity to Human Rights* (Routledge 2015), particularly the Introduction.

medical model. The Disability Discrimination Act 1995 and the Equality Act 2010 promote the social model of disability in establishing legal requirements for adjustments that enable access for disabled people, but hold to the medical model in the definition of disability. Similarly, Morris notes that eligibility for services and benefits 'is still determined by assessment of how much our bodies are affected by impairment and/or illness, rather than the disabling barriers [disabled people] experience'.⁴⁶ In its review of social care legislation, the Law Commission attempted to overcome this hurdle, proposing that eligibility should be stated to depend on need, rather than one's status as a 'disabled person' and that the (then) forthcoming statute should not contain a definition of disability.⁴⁷ In practice, this ambition was only partially successful in England,⁴⁸ and less successful in Wales.⁴⁹ More recently, there have been suggestions that the social model has been co-opted 'by a machinery of government' for its own purposes.⁵⁰

The social model has not gone uncriticised. Shakespeare argues that thinking around the social model has become entrenched, creating a form of 'disability correctness' that has stifled debate and caused the UK movement to stagnate.⁵¹

⁴⁶ Jenny Morris, 'Welfare Reform and the Social Model of Disability' (blogpost, 12 September 2013) <<https://jennymorrisnet.blogspot.com/2013/09/welfare-reform-and-social-model-of.html>> accessed 26 September 2018.

⁴⁷ Law Commission, *Adult Social Care* (Law Com No 326, 2011) paras 12.31-12.33.

⁴⁸ The Care Act 2014 creates a requirement for an assessment on the appearance of need not on the existence of any particular impairment or characteristic, such as age (section 9). However, the Care and Support (Eligibility) Regulations require that need 'arise from or [be] related to a physical or mental impairment or illness'. The term 'disability' is also used in the Act in relation to the power of local authorities to create registers of local disabled adults (section 77). In that section, the phrase 'has a disability' is used, and 'disability' is given the meaning given in the Equality Act 2010.

⁴⁹ The Social Services and Well-being (Wales) Act 2014 also creates a requirement for an assessment on the appearance of need rather than the existence of any particular impairment or characteristic, such as age (section 19). The Care and Support (Eligibility) (Wales) Regulations 2015 require the need to arise from 'the adult's physical or mental ill-health, age, *disability*, dependence on alcohol or drugs, or other similar circumstances' (emphasis added). In addition, section 15(2)(d) of the 2014 Act requires local authorities to provide services that it considers will have the effect of 'minimising the effect on disabled people of their disabilities'. Sections 18(5) and (6) also create a local authority power to establish registers of disabled people. Throughout the Act, the term 'disabled' is held to have the meaning given in the Equality Act 2010 (section 3(5)). In the Regulations 'disability' is not defined.

⁵⁰ Angharad E Beckett and Tom Campbell, 'The Social Model of Disability as an Oppositional Device' (2015) 30(2) *Disability & Society* 270.

⁵¹ Shakespeare, *Rights and Wrongs* (n1), 17-21. Shakespeare notes in this book that his work and criticisms have been controversial within the disabled people's movement and the academic field of disability studies.

Among academic commentators, the social model is contested,⁵² and while the social model has been influential in debates both within and outside the UK,⁵³ Shakespeare notes that movements of disabled people in other countries have achieved notable policy successes based upon different theoretical underpinnings.⁵⁴ Discussion of the value and place of the social model has recently re-emerged among disabled activists in the UK. Various activists who identify as disabled through long term ill-health argue that it is essential to understand the importance of the impact of physical or psychological illness on the person, and have emphasised this in campaigns around welfare reform, prompting concern by some that there is a reversion to narratives of victimhood.⁵⁵ This highly active group of campaigners arguably forms a new movement of 'sick and disabled' people, that engages with, but is to an extent separate from, the earlier 'disabled people's movement'. Despite these issues, the social model remains accepted – even by its critics – as the distinguishing feature that separated UPIAS and later organisations of disabled people from those which had gone before and enabled the development of a wider movement.⁵⁶

4. The development of independent living in the UK

The term 'independent living' was coined in the United States in the late 1960s by a group of disabled students at the Berkeley campus of the University of California. While on campus, the students were required to live in the medical facility, effectively under the authority of medical and rehabilitation staff. Frustrated by their lack of freedom in this segregated unit, the imposition of rules by the medical staff, and a campus that was largely inaccessible to them, the group began to consider ways in

⁵² See for example, Susan Gabel and Susan Peters, 'Presage of a Paradigm Shift? Beyond the Social Model of Disability toward Resistance Theories of Disability' (2004) 19 (6) *Disability & Society* 585.

⁵³ Gabel and Peters state 'the social model of disability has put down substantial roots worldwide' and that the influence of the social model extends into multiple areas including 'international declarations and conventions [and] in national legislation'. *Ibid*, 585.

⁵⁴ Shakespeare, *Rights and Wrongs* (n1) 13-14.

⁵⁵ Jenny Morris, 'Welfare Reform' (n46).

⁵⁶ Shakespeare argues that '[t]he British social model was critical to the disability movement for two reasons' – it 'identified a political strategy' (barrier removal) and it enabled disabled people 'to think of themselves in a totally new way'. Shakespeare also notes that the social model enabled academics to consider disability in new ways. Shakespeare, *Rights and Wrongs* (n1) 12-13.

which they could tackle their consequent marginalisation from university life. Working together, they established a range of services including a personal attendant service and advocacy, which enabled them to become better involved in student activities.⁵⁷

Through this process, the students developed what Zukas has since described as a 'philosophy of disability' incorporating three central elements. These were: that disabled people best know what their needs are and how to meet them; that these needs can be most effectively met by comprehensive programmes providing a variety of services; and that disabled people should be fully integrated into their community.⁵⁸ They called this 'independent living'. Members of the group went on to found the first Center for Independent Living (CIL) in Berkeley and other CILs rapidly followed.⁵⁹ In the early 1980s various disabled activists from the UK visited Berkeley and other US CILs, including John Evans, Philip Mason, Rosalie Wilkins and Vic Finkelstein.⁶⁰

Disabled people in the UK had much in common with the activists in the US. In the UK in the second half of the twentieth century institutionalisation and segregation were the typical experiences for disabled people who could not afford to buy their own support and who either did not want, or did not have the option, to live with and be supported by family members.⁶¹ Institutional living was characterised by inflexible regimes, the control of residents by staff and harassment ranging from petty restrictions to abuse. Mason cited rules imposed by staff which included requirements that residents change into their pyjamas before 6pm, switch televisions

⁵⁷ Hale Zukas, 'The History of the Berkeley Center for Independent Living (CIL)' (Report for the State of the Art Conference, Berkeley Center for Independent Living, 1975) (*Independent Living Institute*, undated) <<https://www.independentliving.org/docs3/zukas.html>> accessed 12 July 2019.

⁵⁸ *Ibid.*

⁵⁹ Gerben DeJong, 'Defining and Implementing the Independent Living Concept' in Nancy M Crewe and Irving Zola (eds) *Independent Living for Physically Disabled People* (Jossey-Bass 1983); Peters, Gabel and Symeonidou (n26). Barnes and Mercer note that '[b]y the late 1990s, there were more than 300 CILs in the US'. Barnes and Mercer, *Independent Futures* (n21) 32.

⁶⁰ John Evans, 'The Independent Living Movement in the UK' (*Independent Living Institute*, 2003) <<https://www.independentliving.org/docs6/evans2003.html#1>> accessed 6 January 2018; HCIL, 'Project 81: One Step On' (unpublished and undated) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-one-step-on.pdf>> accessed 7 December 2017.

⁶¹ Among others, see: HCIL, 'Project 81' (n60). For a history of institutions in the UK, see: Anne Borsay, *Disability and Social Policy in Britain Since 1750* (Palgrave 2005). For a succinct summary, see: Colin Barnes and Geof Mercer, *Exploring Disability* (2nd edn, Polity Press 2010), 128-132.

off by 10.30pm, and obtain staff permission to go out after dark.⁶² It was rebellion against such institutionalisation and its restrictions that led to the development of UPIAS.⁶³

The independent living movement in the UK arose as disabled people rejected these conditions and sought to devise new forms of support which enabled them to be in control of their own lives and live in ordinary local communities.⁶⁴ These early small initiatives effectively complemented the theoretical focus of UPIAS. Priestley argues that they both provided new lived experiences, and demonstrated the possibilities for new forms of self-organised support.⁶⁵ In the late 1970s, the Spinal Injuries Association – a user-controlled service provider organisation formed in 1974 – developed a service that enabled members to be supported by personal assistants in their own homes.⁶⁶ In Derbyshire in the mid-1970s a small group of disabled individuals, including Ken and Maggie Davis, worked with various agencies to develop a small complex of flats. The three ground floor flats were wheelchair accessible and occupied by disabled people, while those on the first floor were let to other individuals who would act as ‘supporting families’ to the disabled tenants when requested, in return for small payments.⁶⁷ This ‘Grove Road scheme’ is recognised as one of the first influential successes by disabled people in the UK in developing and controlling their own support.⁶⁸ A notable feature was its inclusion of both disabled and non-disabled people as tenants.⁶⁹

⁶² Philip Mason, ‘The Place of Le Court Residents in the History of the Disability Movement in England’ (unpublished, 1990) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Mason-le-court-philip-mason.pdf>> accessed 25 May 2018.

⁶³ A portion of the letter by Paul Hunt to *The Guardian* states: ‘the severely physically handicapped, many of whom also find themselves in isolated and unsuitable institutions, where their views are ignored and they are subject to authoritarian and often cruel regimes. I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of these successors to the workhouse.’ Paul Hunt, ‘Letter’ (n4).

⁶⁴ John Evans has produced a comprehensive informal history of the independent living movement in the UK and internationally. John Evans, ‘The Independent Living Movement’ (n60).

⁶⁵ Priestley (n26).

⁶⁶ Barnes and Mercer, *Independent Futures* (n21); Campbell and Oliver (n1) ch 10.

⁶⁷ For a personal account of the development of the scheme, see: Ken Davis, ‘Tenant’s Eye View’ in ‘Disability Challenge Issue 1’ (UPIAS, May 1981) <<http://disability-studies.leeds.ac.uk/files/library/UPIAS-Disability-Challenge1.pdf>> accessed 30 April 2015. The project took four years to complete, beginning in 1972. Barnes and Mercer, *Independent Futures* (n21) 143.

⁶⁸ Oliver and Barnes, *Disabled People and Social Policy* (n1) 82-83. See also, Evans, ‘The Independent Living Movement’ (n60).

⁶⁹ Barnes and Mercer, *Independent Futures* (n21).

At around the same time, a number of individuals living in the Le Court Leonard Cheshire Foundation residential home in Hampshire, including John Evans, were also seeking ways to live on their own terms and in their own homes. Le Court was an institution with a history of resistance by residents to staff control and imposed routines.⁷⁰ In 1979 a group came together under the name 'Project 81'⁷¹ to explore options and move away from Le Court.⁷² Inspired by the Berkeley initiative, the group began a process of negotiation with the local authorities funding their residential placements. The aim was to persuade the authorities that it was feasible (and no more expensive) for them to live in ordinary housing – adapted for their individual needs – in local communities, with support provided by personal assistants employed by themselves. Despite numerous setbacks, all the individuals in Project 81 finally moved into their own homes and obtained financial packages from their local authorities – in the form of cash payments – which they used to employ personal assistants. These initiatives, and particularly the work of Project 81 formed the basis of what is now known as 'independent living' in the UK.⁷³ The cash payments pioneered by Project 81 were the forerunners of what are now called 'direct payments' – the provision by a local authority of sums of money to disabled people, in lieu of social care services, enabling them to purchase their own support.

⁷⁰ Paul Hunt, the founder of UPIAS, spent some time as a resident of Le Court. During this time, he worked to secure the commissioning of research into the experience of individuals living in such institutions. The residents of Le Court took part in the project, and condemned the final publication, which described disabled people in institutions as 'socially dead'. The research is published as E J Miller and G V Gwynne, *A Life Apart* (Tavistock 1972). Paul Hunt's response can be found at Paul Hunt, 'Settling Accounts with the Parasite People: A Critique of "A Life Apart"' in 'Disability Challenge Issue 1' (UPIAS May 1981) <<http://disability-studies.leeds.ac.uk/files/library/UPIAS-Disability-Challenge1.pdf>> accessed 30 April 2015. Philip Mason has written a history of Le Court which includes details of 'actions' by the residents, including Paul Hunt. Philip Mason, 'The Place of Le Court Residents in the History of the Disability Movement in England' (unpublished, 1990) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/Mason-le-court-philip-mason.pdf>> accessed 7 December 2017.

⁷¹ The name 'Project 81' was chosen as 1981 was the United Nations International Year of Disabled People. The group felt that this would provide recognition and impetus for their campaign. See Evans, 'The Independent Living Movement' (n60). The disabled singer Ian Dury named Project 81 'the escape committee'. See, John Evans, 'We Can't Give Up on Independent Living' *The Guardian* (London, 16 July 2014) <<https://www.theguardian.com/society/2014/jul/16/independent-living-fund-closure-disabled-people-residential-care>> accessed 14 May 2018. The full name of the project was, 'Project 81: Consumer Directed Housing and Care'. See Barnes and Mercer, *Exploring Disability* (n61) 143.

⁷² For an account of three of the individuals involved in Project 81, including visits to the USA, see: HCIL, 'Project 81' (n60).

⁷³ The outcome of Project 81 – of individuals living in their own homes and employing PAs through the use of cash payments provided by local authorities has been cited as the first recognisable form of independent living in the UK. Spectrum, 'Celebration to Pay Tribute to John Evans, OBE' (*Spectrum*, 17 January 2014) <<http://spectrumcil.co.uk/events/11/celebration-to-pay-tribute-to-john-evans-obe/>> accessed 6 January 2018.

The name 'independent living', and the principle of buying and controlling one's own support in the form of personal assistance, were borrowed from the Berkeley initiative and demonstrate a more individual and consumerist approach that differed notably from the Marxist heritage of UPIAS. Regardless of its influences, both Evans⁷⁴ and Davis⁷⁵ noted the need for the UK pioneers to adapt the model to work within the context of the UK welfare state.

Also drawing from the US experience, individuals engaged in the struggle to live life on their own terms established CILs and other organisations to support themselves and others. Those involved in both Project 81 and Grove Road went on to found (in 1984⁷⁶) two of the first CILs in the UK,⁷⁷ although the language deployed by the Centres was different. Hampshire Centre for *Independent Living* (founded by individuals including John Evans) worked on developing the use of direct payments by disabled people to obtain personal assistance.⁷⁸ The Derbyshire Centre for *Integrated Living* (DCIL) (founded by Ken Davis and others) concentrated on five core matters identified in Berkeley: personal assistance, accessible housing in the community, accessible transport, general community access and peer support, plus two further needs: accessible information and technical aids and equipment.⁷⁹ Rejecting the idea and language of 'independence' in favour of 'integration', DCIL's priority was to ensure the involvement of non-disabled people in management

⁷⁴ John Evans, 'The Independent Living Movement' (n60). It is of note that Evans, as one of the individuals involved in Project 81 has borrowed freely from the original Berkeley 'philosophy' of independent living. See, for example: John Evans, 'How Disabled People are Excluded from Independent Living' (Conference on European Disabled People, March 2002) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/evans-excluded-Independent-Living-Madrid.pdf>> accessed 8 December 2017.

⁷⁵ Davis and Mullender (n1).

⁷⁶ The precise date of the foundation of these organisations appears differently in different sources. Evans states they were founded in 1984 while Barnes and Mercer state 1985. For Evans, see: John Evans, 'The Independent Living Movement' (n60). For Barnes and Mercer, see Barnes and Mercer, *Exploring Disability* (n61) 143.

⁷⁷ In 1984, CILs were also founded in Southampton and Greenwich. See: Spectrum, 'Spectrum: Our History: 30 Years of Independent Living: 1984-2014' (*Spectrum*, updated 2015) <<http://spectrumcil.co.uk/wp-content/uploads/2015/06/SPECTRUM-Our-History-30-Years-of-Independent-Living-2nd-Edition-May2015-PDF-Version.pdf>> accessed 18 February 2019.

⁷⁸ Maggie Davis, 'Personal Assistance – Notes on the Historic' (paper at BCODP seminar, 'Making Our Own Choices', August 1992) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019, 18.

⁷⁹ *Ibid*, 18.

structures of agencies such as health authorities and social services.⁸⁰ This distinction is discussed in detail in Chapter 8, section 3.1.

Action by disabled people in the UK to move out of institutions and to develop their own ways of living was not confined to the groups of people in Hampshire and Derbyshire. Maggie Davis noted that in the UK in the late 1970s and early 1980s there were various individuals and small groups of disabled people experimenting with different ways of living in non-segregated settings, using various forms of support,⁸¹ and similar initiatives were taking place in other European countries and beyond.⁸² Among inspirations for independent living Davis cites the Fokus group in Sweden, Collectivhaus in Denmark and the Het Dorp community in the Netherlands.⁸³ Similarly, Jolly states that six CILs were established in Finland in 1973 and that in the early 1980s CILs were founded in Canada and an organisation of disabled people was created in Nicaragua to provide 'independent living services and advocacy'. Jolly also refers to advocacy and self-help groups in Switzerland, Zimbabwe and Japan across this timescale. The independent living movement in the UK was therefore taking place against a backdrop of similar initiatives in other countries and continents.

In the UK, the movement was boosted by the establishment in 1988 of the Independent Living Fund (ILF) – a government-initiated and funded, and nationally administered, trust which made grants to people with severe impairments that enabled them to purchase personal assistance.⁸⁴ Internationally, activists generated

⁸⁰ Ken Davis, 'Notes on the Development of the Derbyshire Centre for Integrated Living (DCIL)' (Derbyshire Coalition of Disabled People, December 1984) <<http://disability-studies.leeds.ac.uk/files/library/DavisK-earlydcil.pdf>> accessed 1 June 2015, para 5.1. The document indicates that this co-working extended to non-disabled people being represented on DCIL management structures.

⁸¹ Maggie Davis (n78); John Evans, 'The Independent Living Movement' (n60).

⁸² The first International conference on independent living in Europe was held in Munich in 1982. Barnes and Mercer, *Independent Futures* (n21). John Evans describes the discussion between activists in the UK, Sweden and Berkeley. See: Evans, 'The Independent Living Movement' (n60).

⁸³ Maggie Davis (n78).

⁸⁴ The ILF was developed as a response to difficulties encountered when the government withdrew the Domestic Care Allowance – a benefit paid to disabled people that many had used to purchase personal assistance. Following protest and complaint by disabled people, the ILF was created initially on a short term basis to enable grants to continue to be paid to people with severe impairments. It was funded and administered by the then Department for Health and Social Security. Evans, 'The Independent Living Movement' (n60).

further impetus in 1989 with a conference in Strasbourg. At this conference, delegates produced the 'Strasbourg Resolutions' – a series of demands for rights to personal assistance and the end of institutionalisation⁸⁵ – and founded the European Network on Independent Living (ENIL).⁸⁶ Independent living was swiftly placed at the heart of the disabled people's movement in the UK, with a UK 'independent living movement' growing up within and alongside it. Following Strasbourg, the British Council of Organisations of Disabled People (BCODP)⁸⁷ established an independent living committee and launched a campaign for the legal recognition of direct payments.⁸⁸ Legislation to this effect was finally passed in 1996 in the form of the Community Care (Direct Payments) Act 1996, and in the same year BCODP founded the National Centre for Independent Living (NCIL).⁸⁹ A further development was the extension of the reach of independent living to those with conditions affecting cognitive and communication functioning. Independent living was pioneered by individuals with physical impairments who on occasion contrasted themselves with people in these groups.⁹⁰ Yet from the outset of the disabled people's movement, and the early days of independent living, parallels were drawn with other groups, including people with learning disabilities and mental health service users.⁹¹

⁸⁵ European Network for Independent Living, 'The Strasbourg Resolutions' (1989) (*Independent Living Institute*, undated) <<https://www.independentliving.org/docs2/enilstrasbourgresolutions.html>> accessed 14 May 2018.

⁸⁶ Evans, 'The Independent Living Movement' (n60).

⁸⁷ The BCODP was a national network of DPOs founded in 1981 which represented the UK on the international network Disabled People's International (DPI). For an account of the history of the BCODP see, Campbell and Oliver (n1).

⁸⁸ Initially it was unlawful under for local authorities to provide funds directly to individuals to pay for any form of social care support. (National Assistance Act 1948 s29(6)(a) and National Health Service Act 1977 Sch 8 para 2(2) – now both repealed). In the case of the pioneers of independent living and direct payments, this difficulty was overcome by local authorities agreeing to pay monies to an intermediary, who would pass it on to the individual concerned. In relation to the individuals from Project 81, for example, the monies were paid to Le Court residential home, which then paid the equivalent sum to the individuals. This legal position discouraged many local authorities from making payments and inhibited the spread of similar schemes. See, Evans, 'The Independent Living Movement' (n60).

⁸⁹ Evans, 'The Independent Living Movement' (n60). NCIL was funded by the Department of Health and had a remit to promote independent living and direct payments. In recent work Oliver and Barnes have argued that NCIL was one of a number of 'semi-independent organizations or quangos' which are detrimental to the disabled people's movement as they require compromised principles and use funding which might otherwise go to independent DPOs. Oliver and Barnes, *The New Politics of Disablement* (Palgrave Macmillan 2012), 170.

⁹⁰ Brisenden, for example, expressed frustration about people with physical impairments being seen as 'morons' or 'equated with a raving, dribbling, idiot'. Simon Brisenden, 'Independent Living and the Medical Model of Disability' (1986) *Disability, Handicap & Society* 1(2) 173, 175 and 174 respectively.

⁹¹ In 1974 UPIAS argued that the Union was specifically for individuals with physical impairment but stated that, '[s]ome, such as people who are called "mentally handicapped", or those "mentally ill",

As independent living took hold in the movement, its content developed. It is noted above that the Berkeley CIL focused on five matters, described as ‘needs’ for disabled people to achieve independent living, which were expanded to seven by DCIL. As other CILs were founded further matters were added, including an adequate income, access to employment, access to education, and advocacy and training.⁹² More recently access to adequate health services have also been recognised as a further need.⁹³ These matters together are now commonly known in the UK as the 12 ‘basic needs’ or ‘pillars’ of independent living. In full, these pillars are:

- accessible housing;
- personal assistance;
- accessible transport;
- general community and environmental access;
- peer support / counselling;

clearly have a great deal in common with us’. UPIAS, ‘Policy Statement’ (n10) para 22. In 1986 Oliver included these groups among disabled people. Mike Oliver, ‘Social Policy and Disability – Some Theoretical Issues’ (1986) 1(1) *Disability, Handicap & Society* 5, 9. In relation to independent living, see also BCODP, ‘Comment on the Report of the Audit Commission “Making a Reality of Community Care”’ (BCODP, August 1987)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/BCODP-report-of-audit-comm.pdf>> accessed 19 November 2016, para 1.3; and HCIL, ‘HCIL Papers 1990: Independent Living’ (1990) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-hcil.pdf>> accessed 16 November 2016. In the texts examined in this study, the first unequivocal and emphatic statement that people with cognitive impairments should be brought into the idea of independent living was made in 1999. Jenny Morris, ‘The Meaning of Independent Living in the 3rd Millennium’ (presentation at University of Glasgow Centre for Disability Research, May 1999) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/morris-The-meaning-of-independent-living-in-the-new-millenium.pdf>> accessed 18 November 2016, 13-14. In 2001, Oliver considered how it could extend also to older people. Mike Oliver, ‘Where Will Older People Be? Independent Living versus Residential Care’ (paper for conference: The Care and Management of Older People with Complex Needs, London June 2001) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Oliver-where-will-older-people-be.pdf>> accessed 21 September 2017. For discussion of issues relating to independent living and individuals with restricted mental capacity, see Chapter 6.

⁹² Evans, ‘The Role of Centres of Independent/Integrated Living and Networks of Disabled People’ (paper presented at the BCODP seminar, ‘Making Our Own Choices’, 1992) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019.

⁹³ Jenny Morris, ‘Barriers to Independent Living: A Scoping Paper Prepared for the Disability Rights Commission’ (2003) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/morris-independent-living-scoping-paper-final-edit.pdf.pdf>> accessed 27 September 2018, 6-7.

- accessible information;
- technical aids and equipment;
- employment;
- education and training;
- adequate income;
- advocacy and self-advocacy;
- accessible health care.⁹⁴

These developments on independent living occurred alongside other developments in the UK disabled people's movement. Actions of civil disobedience by disabled people led to the formation of the disability movement's Direct Action Network (DAN) in 1991.⁹⁵ Direct action was used to draw attention to matters ranging from a lack of accessible transport to degrading media depictions of disabled people, and simultaneously challenged images of disabled people as passive and vulnerable.⁹⁶ Various disabled activists have noted the powerful impact of such actions on their own consciousness.⁹⁷ Similarly, a small but powerful disability arts movement developed, in which disabled people explored, developed and took ownership of their impairments and identities through mediums including poetry, visual art, film and song that were experienced and seen as acts of resistance and as a means of celebrating and affirming a claimed 'disabled identity'.⁹⁸

⁹⁴ Ibid. These are the 12 pillars as listed by certain activists including Morris, citing Southampton CIL (now Spectrum). Other activists recognise slightly different permutations. Eleven needs are frequently cited, with the missing need being 'accessible health care'. This is the most recent need to be recognised and added to the pillars.

⁹⁵ Campbell and Oliver (n1). A particularly notable event occurred in 1998 when a march by disabled people on the offices of the then Department of Health and Social Security led to an unplanned demonstration in which disabled people sat down in the road, blocking the traffic (152-153).

⁹⁶ Damon Rose, 'When Disabled People Took to the Streets to Change the Law' (*BBC*, 7 November 2015) <<https://www.bbc.co.uk/news/disability-34732084>> accessed 26 September 2018.

⁹⁷ Campbell and Oliver (n1), 153-155. Shakespeare, 'Disabled People's Self-Organisation' (n26), citing Jenny Morris, *Pride Against Prejudice* (Women's Press 1991). In the US context, Zola notes a similar impact and the impact of such action on 'the stereotype of the disabled person as powerless'. Irving Zola, 'Developing New Self-Images and Interdependence' in Nancy M Crewe and Irving Zola (eds) *Independent Living for Physically Disabled People* (Jossey-Bass 1983), 56.

⁹⁸ See, among many examples: Campbell and Oliver (n1); Sheila Riddell and Nick Watson (eds), *Disability, Culture and Identity* (Routledge 2003); and Lennard J Davis (ed), *The Disability Studies Reader* (3rd edn, Routledge 2010) Part VI. The London Disability Arts Forum was formed in 1987 – see Campbell and Oliver (n1) 111. In Wales, the organisation Disability Arts Cymru is a particular focus. See Disability Arts Cymru at <<https://www.disabilityartscymru.co.uk/>> accessed 8 March 2019. Swain and French argued that disability arts was a central element of what they described as an 'affirmation model' of disability, which encompassed impairment as well as disability in positive

In campaigning terms, a stronger focus on rights and discrimination developed. This echoed ideas established in the disabled people's movement in the US, which itself borrowed from the African American civil rights movement and deployed mass political action alongside lobbying for anti-discrimination legislation (ADL).⁹⁹ Disabled people's organisations in the UK certainly echoed these ideas, particularly in its use of the language of segregation and rights which was highly resonant in the US civil rights movement.¹⁰⁰ Initially, however, the idea of 'rights not charity' remained more associated with the US movement.¹⁰¹ In the UK during the earlier years of the movement the main focus was placed on policy and legislative change in relation to the UK's more highly developed welfare state.¹⁰² Early UK activists were clear that the UK movement was 'rooted in its own historical and material conditions'.¹⁰³

BCODP committed to ADL in 1989.¹⁰⁴ In the UK, the campaign for ADL was given particular impetus by the work on the impact of discrimination by Barnes¹⁰⁵ and the passing in the US of the Americans with Disabilities Act 1990¹⁰⁶ – a statute that acted as an inspiration for ADL in various countries.¹⁰⁷ The first piece of disability-

individual and collective identities. John Swain and Sally French, 'Towards an Affirmation Model of Disability' (2000) 15(4) *Disability & Society* 569. See also Shakespeare, *Rights and Wrongs* (n1) 107.
⁹⁹ Barnes and Mercer, *Exploring Disability* (n61).

¹⁰⁰ This was particularly the case with UPIAS, as the name indicates, whose members placed segregation and exclusion at the heart of their campaigning message. Whether this was an intentional reference to or borrowing from the US civil rights movement is not clear. There was a debate as to whether the organisation should be called the Union 'against segregation' or 'for integration'. Campbell and Oliver (n1) 66. UPIAS also deployed the language of rights, both in relation to their common humanity and in particular situations, such as their position as residents in segregated institutions. UPIAS, 'Policy Statement' (n10).

¹⁰¹ Barnes and Mercer, *Independent Futures* (n21) 34. Barnes and Oliver note, however, that the first 'Rights not Charity' march in Britain took place in July 1988. Oliver and Barnes, *Disabled People and Social Policy* (n1) 75.

¹⁰² Barnes and Mercer, *Exploring Disability* (n61). Elsewhere Barnes and Mercer suggest that this focus on local policy and national legislation was influenced in part by a 'reaction to the involvement of national charities in conventional political lobbying'. Barnes and Mercer, *Independent Futures* (n21) 34.

¹⁰³ Campbell and Oliver, (n1) 49. This distinction may have been emphasised because of the Marxist heritage of the early movement in the UK.

¹⁰⁴ *Ibid*, 138.

¹⁰⁵ In particular, the work of Barnes that was sponsored by BCODP: Colin Barnes, *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation* (Hurst & Co 1991).

¹⁰⁶ Barnes cites the ADA 1990 as one reason for a shift in government thinking on ADL in the UK.

Colin Barnes, 'Independent Futures: Policies, Practices and the Illusion of Inclusion' (presentation to the European Network for Independent Living, November 2006)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-valencia-presentation-Colin.pdf>> accessed 18 November 2016.

¹⁰⁷ Kanter (n45) 37.

focused ADL in the UK was the Disability Discrimination Act 1995, although there were serious reservations about this statute among activists.¹⁰⁸ The Disability Rights Commission (DRC) was established by statute in 2000¹⁰⁹ as a state funded organisation with a remit to support the implementation of the 1995 Act and conduct wider work relating to disability discrimination. A number of influential disabled activists became connected to the DRC.¹¹⁰ In 2010 the Equality Act 2010 brought a range of anti-discrimination legislation into one overarching statute, and the DRC was absorbed into the newly-founded Equality and Human Rights Commission (EHRC).

By the dawn of the new millennium, independent living had become one of the central policy demands of the DRC.¹¹¹ In 2002, the DRC created a definition of independent living that has been widely cited in England.¹¹² It states:

The term independent living refers to all disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.¹¹³

¹⁰⁸ Activists were concerned in particular about the use of the medical model to define disability and the limited scope of the Act, even following subsequent amendments that extended its range. See, Barnes, 'Independent Futures' (n106). Ken Davis argued that these limitations led to the 'wholesale rejection by the disabled people's movement and its supporters'. Davis, 'Power' (n11) 3.

¹⁰⁹ The Disability Rights Commission Act 1999 (now repealed).

¹¹⁰ These included Jane Campbell (now Baroness Campbell of Surbiton) and Gerry Zarb, each of whom authored pieces that were among the texts studied in this project. Campbell served as a Commissioner for both the DRC and the EHRC. Zarb held a number of high level posts in the DRC and EHRC, including Head of Health and Independent Living and Head of Health and Social Care Strategy.

¹¹¹ Disability Rights Commission, 'Learning Lessons: The Independent Living Bill – Building Strategic Alliances' (undated) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/DRC-Learning-lessons-the-independent-living-bill.pdf>> accessed 25 May 2018.

¹¹² This definition has been cited as the definition of independent living in various government documents devised in close cooperation with disabled people, including the then pivotal 'Improving the Life Chances of Disabled People' (PMSU n44) and the cross-government 'Independent Living Strategy'. Office for Disability Issues, 'Independent Living: A Cross-Government Strategy about Independent Living for Disabled People' (HM Government, 2008).

¹¹³ Disability Rights Commission, 'Policy Statement on Social Care and Independent Living' (October 2002). Provided to the author by e-mail from the Equality and Human Rights Commission (28 May 2015).

The disabled people's movement also campaigned for a right to independent living to be enshrined in domestic legislation.¹¹⁴ This campaign was taken up by the DRC and at parliamentary level.¹¹⁵ The DRC worked with a number of organisations and the disabled peer Lord Ashley of Stoke to develop a private member's bill to this effect.¹¹⁶ Such bills were introduced to parliament on four occasions between 2005 and 2009,¹¹⁷ none of which were enacted. In Wales, Disability Wales has also called for a legal right to independent living.¹¹⁸ These calls have recently been echoed and reiterated by the EHRC.¹¹⁹

Internationally, a critical step forward in the development of independent living came with the development and ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), adopted on 13 December 2006 following five years of negotiations.¹²⁰ Article 19 of the UNCRPD creates the right of disabled people to live independently and be included in the community – the first time that the right to

¹¹⁴ John Evans, 'The Importance of CILs in Our Movement' (presentation 2nd November 2006) <<http://disability-studies.leeds.ac.uk/files/library/evans-Valencia-CIL-Presentation-john.pdf>> accessed 11 May 2015.

¹¹⁵ Gerry Zarb, 'Why We Need a Legal Right to Independent Living' (presentation, European Congress on Independent Living, Tenerife, 24th - 26th April 2003) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Zarb-Zarb-Independent-Living.pdf>> accessed 12 July 2019. While this move was supported by the disabled people's movement, there was also concern that legislative attempts on independent living should remain under the control of the movement, rather than the DRC. In 2006 Evans stated that: "the important thing is that WE ARE in control of this process and not the Disability Rights Commission". Evans, 'The Importance of CILs' (n114).

¹¹⁶ Disability Rights Commission, 'Learning Lessons' (n111).

¹¹⁷ Joint Committee on Human Rights, *Implementation of the Right of Disabled People to Independent Living* (2010-12, HL 257, HC 1074) para 55 including footnote.

¹¹⁸ Disability Wales, 'Disabled People's Manifesto: Creating an Enabling Wales' (*Disability Wales*, 2016) <<http://www.disabilitywales.org/wordpress/wp-content/uploads/DW-Manifesto-BILINGUAL-FINAL.pdf>> accessed 9 November 2016 (no longer available online but copy archived by the author).

¹¹⁹ John Pring, 'Watchdog's Barrister Calls for Legal Right to Independent Living' (*Disability News Service*, 28 June 2018) <<https://www.disabilitynewsservice.com/watchdogs-barrister-calls-for-legal-right-to-independent-living/>> accessed 18 June 2019.

¹²⁰ Arlene Kanter (n45) 21. Kanter notes (at 39) that a UN convention on disability was first proposed by Italy in 1987, and that international support for such a move became widespread in March 2000 at the first world NGO Summit on Disability in Beijing, which led to the *Beijing Declaration on the Rights of People with Disabilities in the New Century* (UN General Assembly Economic and Social Council, May 2000). The Beijing Declaration called for a UN convention 'that would legally bind nations to promote the full inclusion of people with disabilities, the elimination of discriminatory attitudes and practices, and an improved quality of life for people with disabilities'. The Beijing Declaration can be found at <<http://www.un.org/documents/ecosoc/docs/2000/e2000-47.pdf>> accessed 30 May 2018. For an examination of the rights available to disabled people in international provisions prior to the UNCRPD and the need for the development of the UNCRPD, see, Anna Lawson, 'The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?' (2008) 34 *Syracuse J Int'l L & Com* 563.

community living has been recognised in international law.¹²¹ The full text of Article 19 reads:

Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The UNCRPD was devised not simply to establish a series of rights, but to alter narratives and legal identities around disability. As a whole, it replaces a construction of disabled people as objects of charity and welfare with one that establishes them as active subjects and as equal citizens, legal persons and rights holders.¹²² Article 19 is one of the key provisions contributing to this shift,¹²³ particularly in conjunction with Article 12, which recognises disabled people as legally capacitated citizens on

¹²¹ Arlene Kanter (n45) ch 2.

¹²² Arlene Kanter (n45) particularly Introduction; T Hammarberg, 'Disability Rights' (n40).

¹²³ Kanter states that without the right to live in a home in the community 'you cannot vote, travel, enrol in school, apply for a job, or receive government benefits, raise a family, access health care, or open a bank account'. Kanter (n45) 12.

an equal basis with others, and Article 3, which demands '[r]espect for ... individual autonomy including the freedom to make one's own choices, and independence of persons'. Article 8 contains a number of requirements relating to awareness raising, which include challenging stereotypes of disabled people and creating positive perceptions.¹²⁴

Following the adoption and UK ratification of the UNCRPD, in 2006 and 2009 respectively, disabled activists have focused increasingly on Article 19 in their campaigns for independent living.¹²⁵ The implementation of Article 19 was the focus of a report by the parliamentary Joint Committee on Human Rights in 2012, which also argued that a right to independent living should be incorporated into domestic social care law.¹²⁶ It should be noted that in the UNCRPD the phrase 'living independently' rather than 'independent living' was intentionally used to avoid alignment with any specific national movement.¹²⁷ However, the CRPD Committee recently produced a general comment on Article 19 in which the phrase 'independent living' is frequently deployed.¹²⁸

¹²⁴ See further, Chapter 6, section 5.

¹²⁵ Joint Committee on Human Rights (n117) 62.

¹²⁶ Ibid. The report concluded that there was a 'risk of retrogression' in relation to independent living, with various policy developments and the context of spending cuts combining to produce a cumulative detrimental impact. Among the numerous potentially damaging changes cited were reductions in local authority funding, changes to Disability Living Allowance, caps on housing benefit, the closure of the ILF; and tightening eligibility criteria for social care. In addition, the Joint Committee noted concerns both that the impact of reforms on disabled people had been inadequately assessed and that there had been a failure to place the UNCRPD at the centre of policy development (pages 4-8).

¹²⁷ János Fiala-Butora, Arie Rimmerman, and Ayelet Gur, 'Article 19: Living Independently and Being Included in the Community' in Ilias Bantekas, Michael Stein and Demetres Anastasiou (eds) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018). Collingbourne states, 'During drafting of Article 19, the interpretation of "independent living" was contentious, with some stressing that it should not be seen as endorsing the disabled people's independent living movement.... consensus was eventually reached for using the term "living independently" with the understanding that it was intended to reinforce the concept of "community living"'. Tabitha Collingbourne, 'The Care Act 2014: A Missed Opportunity?' (2014) 20(3) *European Journal of Current Legal Issues* <<http://webjcli.org/article/view/365/464>> accessed 16 October 2015. The immediate author commented on the use of the phrase 'living independently' in a response to the consultation by the UN Committee on the Rights of Persons with Disabilities on the Committee's Draft General Comment No. 5, arguing that it created scope for confusion for reasons that are explored later in this thesis (Chapter 8). Emily Kakoullis, Lucy Series and Alison Tarrant, *Comments on the Committee on the Rights of Persons with Disabilities Draft General Comment No. 5: Article 19 CRPD: Living Independently and being Included in the Community* (2017) <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/WSArticle19.aspx>> accessed 19 March 2019.

¹²⁸ Committee on the Rights of Persons with Disabilities, 'General Comment No. 5 on Article 19: Living Independently and Being Included in the Community' (UN Doc CRPD/C/18/1, adopted on 29 August 2017) <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>> accessed 12 July 2019.

Article 19 of the UNCRPD reflects the fact that independent living and the independent living movement are global phenomena. The international nature of the development of independent living is noted earlier in this section. Although this thesis focuses solely on independent living in the UK, and specifically Wales, activism around independent living is situated within a broader, worldwide context. There are strong independent living campaigns and movements in the global north, particularly Europe,¹²⁹ the Nordic states,¹³⁰ and North America,¹³¹ and evidence of independent living as a focal point of campaigning also in Asia,¹³² Africa,¹³³ South America and the Middle East.¹³⁴ There are cultural distinctions in how independent living is conceptualised in different regions and countries,¹³⁵ but the general principles of non-institutionalism, self-determination, inclusion and equality remain constant.¹³⁶ Globally, a particular focus is on living arrangements, deinstitutionalisation, and community living, which are the central elements of Article 19 and are rights which remain poorly implemented in multiple countries, including those in the global north.¹³⁷

¹²⁹ See, for example, a recent publication by the European Network for Independent Living, which cited 'independent living heroes' from European countries including the UK, Ireland, Spain, Belgium, Norway, Sweden, Serbia, Slovenia, Germany, Italy, Bulgaria, Hungary and Greece. ENIL, 'Independent Living Heroes: Past Present and Future' (ENIL, 2017) <<https://enil.eu/wp-content/uploads/2017/10/Independent-Living-Heroes-%E2%80%93-Past-Present-and-Future.pdf>> accessed 13 July 2019.

¹³⁰ Ciara Brennan, 'Article 19 and the Nordic experience of Independent Living and Personal Assistance' in P Blanck and E Flynn (eds) *Routledge Handbook of Disability Law and Human Rights* (Routledge 2017).

¹³¹ See, for example, Kathy Martinez, 'Independent Living in the U.S. & Canada' (*Independent Living Institute*, 2004) <<https://www.independentliving.org/docs6/martinez2003.html>> accessed 20 June 2019. Independent Living Canada, a national association of CILs is at: <https://www.ilcanada.ca/> accessed 20 June 2019.

¹³² For example, Reiko Hayashi & Masako Okuhira, 'The Independent Living Movement in Asia: Solidarity from Japan (2008) 23(5) Disability & Society, 417; Chen Yang, 'Being Independent from Whom? Analysing two Interpretations in the Paradigm of "Independent Living"' (2014) 29(5) Disability & Society 671.

¹³³ Joshua T Malinga, 'The African View of Independent Living' (*Independent Living Institute*, 2003) <<https://www.independentliving.org/docs6/malinga2003.htm>> accessed 20 June 2019.

¹³⁴ Inclusion International, 'Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and be Included in the Community' (2012) <<https://inclusion-international.org/wp-content/uploads/2010/05/Global-Report-Living-Colour-dr2-2.pdf>> accessed 20 June 2019.

¹³⁵ Joshua T Malinga (n133).

¹³⁶ Inclusion International, 'Inclusive Communities = Stronger Communities: Global Report on Article 19: The Right to Live and be Included in the Community' (2012) <<https://inclusion-international.org/wp-content/uploads/2010/05/Global-Report-Living-Colour-dr2-2.pdf>> accessed 20 June 2019.

¹³⁷ Kanter (n45) particularly ch 2; János Fiala-Butora, Arie Rimmerman, and Ayelet Gur, (n127).

In the UK, in policy terms, disabled activists have had some noted successes. Independent living has been expressly incorporated into both English and Welsh policy.¹³⁸ In Wales, this was largely as a result of a campaign called 'Independent Living NOW!' led by Disability Wales, which had various aims, including raising awareness of independent living, and the development of both a manifesto on independent living in Wales and a Welsh national independent living strategy.¹³⁹ Independent living is referenced in the guidance on the wellbeing duties under both the Care Act 2014 and the Social Services and Well-being (Wales) Act 2014 (see Chapter 11). Alongside these achievements, work in the disabled people's movement has also continued to focus on the development of CILs and other DPOs. At the time of writing there was no definitive list of DPOs in England or Wales, or the UK more widely, although it was clear that few existed in Wales (see Chapter 3, section 4).

Over the last few years, the focus on the disabled people's movement in relation to independent living has often been on failure, in terms of both the engagement of government policy with independent living and the implementation of practical measures to support it. Morris¹⁴⁰ has expressed concern that the 2008 *Independent Living Strategy* (relevant to England)¹⁴¹ has been abandoned and replaced by a new government strategy, *Fulfilling Potential*¹⁴² - a strategy which rarely deploys the term

¹³⁸ In England, independent living was introduced as a core theme to policy on disability in 'Improving the Life Chances of Disabled People (PMSU, n44) and followed by the 'Independent Living Strategy', published in 2008 (n112). In Wales, it was introduced through the 2013 Welsh Government document, *A Framework for Action on Independent Living* (n43).

¹³⁹ Disability Wales / Anabledd Cymru, 'Manifesto for Independent Living' (2011) <http://www.disabilitywales.org/wordpress/wp-content/uploads/Manifesto_for_IL_E.pdf> accessed 11 November 2016. For an indication of how this campaign, in tandem with the Joint Committee 2010 investigation (n117), influenced the Welsh Government's decision to create a strategy on independent living, see Chapter 3, section 6.2.

¹⁴⁰ Jenny Morris, 'Independent Living and Disabled People' in Liam Foster and others (eds) *In Defence of Welfare 2* (Social Policy Association 2015) <http://www.social-policy.org.uk/wordpress/wp-content/uploads/2015/04/IDOW-Complete-text-4-online_secured-compressed.pdf> accessed 25 May 2018.

¹⁴¹ ODI (n112).

¹⁴² The 'gateway' page for Fulfilling Potential is at, Gov.UK, 'Fulfilling Potential' (last updated 4 September 2014) <<https://www.gov.uk/government/publications/fulfilling-potential-making-it-happen-for-disabled-people>> accessed 12 July 2019. The main documents are: Department for Work and Pensions, 'Fulfilling Potential: Making It Happen' (DWP July 2013); and Department for Work and Pensions, 'Action Plan: Fulfilling Potential – Making it Happen' (DWP July 2013). 'Fulfilling Potential' applies to England in relation to devolved matters and the UK as a whole in relation to non-devolved matters, including benefits, equality and legislation on mental capacity and mental health.

‘independent living’,¹⁴³ and which was itself reported as discontinued in March 2018.¹⁴⁴ In 2014, research by Morris found that opportunities for independent living were diminishing,¹⁴⁵ and in 2015 Inclusion London argued that ‘independent living as a right and as a way of life, is being systematically dismantled’.¹⁴⁶ A conference of disabled campaigners in November 2017 reported a number of problems in enabling independent living, particularly in relation to cuts to social care support, describing the recent situation as ‘a catastrophe’¹⁴⁷ - language which echoed that of the Chair of the UN Committee on the Rights of Persons with Disabilities following its periodic report on the UK.¹⁴⁸ In January 2019 the Reclaiming our Futures Alliance (ROFA) also argued that independent living was at risk.¹⁴⁹

¹⁴³ ‘Fulfilling Potential – Making It Happen’ (n142) contains six substantive references to independent living (including an explicit commitment to independent living and to the UNCRPD). ‘Fulfilling Potential – Making It Happen: Action Plan’ (n142) has one substantive reference.

¹⁴⁴ John Pring, ‘Scrapped! Ministers “Secretly Ditch Government’s Disability Strategy”’ (*Disability News Service*, 22 March 2018) <<https://www.disabilitynewsservice.com/scrapped-ministers-secretly-ditch-governments-disability-strategy/>> accessed 25 May 2018. This apparent discontinuation has not been confirmed by the UK government, and the strategy remains available on the UK.Gov website. There is no indication there that it has been withdrawn, although the last stated update at the time of writing was on 4 September 2014.

¹⁴⁵ Jenny Morris, ‘Independent Living Strategy: A Review of Progress’ (In Control and Disability Rights UK July 2014) <<http://www.disabilityrightsuk.org/sites/default/files/pdf/IndependentLivingStrategy-A%20review%20of%20progress.pdf>> accessed 7 October 2015. Findings included that there was no evidence of significant progress in disabled people’s experience of choice and control in their lives since publication of the Independent Living Strategy, and that there were diminishing opportunities for people to participate in family and community life, reductions in advocacy services, static employment figures, a drop in household incomes for large numbers of disabled people; and an increasing risk of institutionalisation for people with high support needs.

¹⁴⁶ Inclusion London, ‘Evidence of Breaches of Disabled People’s Rights’ (2015) <<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/equality-and-human-rights/evidence-of-breaches-of-disabled-peoples-rights-under-the-un-convention-on-the-rights-of-persons-with-disabilities/>> accessed 2 January 2017, 8.

¹⁴⁷ John Pring, ‘Conference Plans Fightback against Independent Living “Catastrophe”’ (*Disability News Service*, 30 November 2017) <<https://www.disabilitynewsservice.com/conference-plans-fightback-against-independent-living-catastrophe/>> accessed 28 May 2018.

<<https://www.independent.co.uk/news/uk/politics/government-spending-cuts-human-catastrophe-un-committee-rights-persons-with-disabilities-disabled-a7911556.html>> accessed 26 September 2018.

¹⁴⁸ Benjamin Kentish, ‘Government Cuts Have Caused “Human Catastrophe” for Disabled, UN Committee Says’ *The Independent* (London, 25 August 2017)

<<https://www.independent.co.uk/news/uk/politics/government-spending-cuts-human-catastrophe-un-committee-rights-persons-with-disabilities-disabled-a7911556.html>> accessed 26 September 2018.

The report of the Committee is, Committee of the Rights of Persons with Disabilities, ‘Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland’ (3 October 2017)

<https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/C/O/1&Lang=En> accessed 18 February 2019.

¹⁴⁹ ROFA, ‘Independent Living for the Future’ (*Disabled People Against Cuts*, 8 January 2019)

<<https://dpac.uk.net/2019/01/independent-living-for-the-future/>> accessed 18 February 2019. Activists have also recently argued that DPOs and other user-led organisations ‘face extinction’. This group includes CILs. John Pring, ‘User-Led Sector “Faces Threat of Extinction”’ (*Disability News Service*, 14

These concerns have been independently substantiated. In October 2015, following a number of complaints by disabled people, the UN Committee on the Rights of Persons with Disabilities conducted an inquiry into alleged breaches of various articles of the UNCRPD, including Article 19, and found evidence of ‘grave or systematic violations’ of these rights.¹⁵⁰ Among the causes of these violations was the closure of the ILF – a move that was strongly contested by disabled activists and DPOs¹⁵¹ and continues to be the focus of a vigorous campaign in Wales.¹⁵² A recent report by the EHRC provided evidence of continuing inequality between disabled and non-disabled people, in many areas and stated that the combination of increasing demand and reduced funding for social care ‘may be leading to a regression in disabled people’s article 19 rights to live independently in the community.’¹⁵³

February 2019) <<https://www.disabilitynewsservice.com/user-led-sector-faces-threat-of-extinction/>> accessed 20 February 2019.

¹⁵⁰ Committee on the Rights of Persons with Disabilities, ‘Inquiry Concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 6 of the Optional Protocol to the Convention: Report of the Committee’ (6 October 2016) <https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=5&ved=0ahUKEwj0t-qYvqHbAhWkJ8AKHZ0YCMwQFghZMAQ&url=http%3A%2F%2Fwww.ohchr.org%2FDocuments%2FHRBodies%2FCRPD%2FCRPD.C.15.R.2.Rev.1-ENG.doc&usq=AOvVaw2S_N5fMojlKPNueGWBhDhr> accessed 25 May 2018.

¹⁵¹ The ILF was closed despite legal challenge from disabled people on 30 June 2015, with funds dispersed in England to local authorities and in Wales and Scotland to the national governments. The relevant legal cases are, *R (on the application of Bracking) v Secretary of State for Work and Pensions* [2013] EWHC 897 (Admin) and *Stuart Bracking and others v Secretary of State for Work and Pensions* [2013] EWCA Civ 1345.

¹⁵² In Wales, the Welsh Government provided a grant to local authorities to provide to former ILF recipients the same level of funding that they had previously received from the ILF until 31 March 2017 (the Welsh Independent Living Grant, ‘WILG’). The original aim was for local authorities to reassess individuals and transfer them to support funded solely by local authorities under the Social Services and Well-being (Wales) Act 2014 between 1 April 2017 and 31 March 2019. See, Disability Rights UK, ‘Independent Living Fund Replacement Schemes: Factsheet F69’ (*DRUK*, 5 August 2015) <<http://www.disabilityrightsuk.org/independent-living-fund>> accessed 20 October 2015; and Welsh Government, ‘The Welsh Independent Living Grant’ (*Welsh Government*, 3 November 2017) <<https://gov.wales/topics/health/socialcare/wilg/?lang=en>> accessed 25 May 2018. A campaign to save the WILG is ongoing at the time of writing, fought particularly by one individual and allies. See: Nathan Lee Davies, ‘#SAVEWILGCAMPAIGN’ (undated) <<https://nathanleedavies.wordpress.com/save-wilg-campaign/>> accessed 25 May 2018. At the time of writing this campaign had secured a significant concession in the form of a promise from the Welsh Government that anyone concerned about a reduction in their support on reassessment could request a further assessment from an independent social worker. See the statement by the Minister, Julie Morgan AM, Deputy Minister for Health and Social Services, ‘Written Statement: Welsh Independent Living Grant’ (*Welsh Government*, 12 February 2019) <<https://beta.gov.wales/written-statement-welsh-independent-living-grant>> accessed 18 February 2019.

¹⁵³ EHRC, ‘Progress on Disability Rights in the United Kingdom: UK Independent Mechanism Update Report to the UN Committee on the Rights of Persons with Disabilities’ (EHRC, 2018) <<https://www.equalityhumanrights.com/sites/default/files/progress-on-disability-rights-in-the-uk-crpd-shadow-report-2018.pdf>> accessed 18 February 2019.

Similarly, a recent EHRC report on equality in Wales found serious inequalities between disabled and non-disabled people in areas including income, health and life expectancy, education, employment, housing and social participation.¹⁵⁴ This report argued that '[t]here should be a sharp focus on improving life in Wales for disabled people' and that the Welsh Government should incorporate the UNCRPD into Welsh legislation.¹⁵⁵

Various responses have been suggested by disabled activists to these circumstances. Beresford and Harris have suggested that the solution is to establish a legal right to independent living and a nationally funded 'national independent living service'.¹⁵⁶ At the time of writing a campaign for such a service had recently been launched by Disabled People Against Cuts and ROFA.¹⁵⁷ The service would be 'co-created between government and disabled people, funded through general taxation, managed by central government, led by disabled people, and delivered locally in co-production with disabled people'.¹⁵⁸ At the November 2017 conference mentioned above it was also indicated that the EHRC was seeking legal advice as to how independent living could be enshrined or better protected in domestic legislation.¹⁵⁹

More recently, however, Morris has suggested that it may be time for the disabled people's movement to 'admit defeat and abandon the term "independent living" to

¹⁵⁴ EHRC, 'Is Wales Fairer? The State of Equality and Human Rights 2018' (EHRC, 2018) <<https://www.equalityhumanrights.com/sites/default/files/is-britain-fairer-2018-is-wales-fairer.pdf>> accessed 18 February 2019.

¹⁵⁵ Ibid, 9.

¹⁵⁶ Peter Beresford and Mark Harrison, 'Social Care is Broken Beyond Repair – So What Should Replace It?' (Labour Briefing, 24 November 2017) <<http://labourbriefing.squarespace.com/home/2017/11/24/ayugootu1ts3hj752d342uv1wn9778>> accessed 28 May 2018.

¹⁵⁷ These groups have launched a campaign for 'a National Independent Living Support Service capable of upholding disabled people's rights to independent living and building on what was so effective about the Independent Living Fund'. Disabled People Against Cuts, 'Motion – National Independent Living Support Service' (18 February 2019) <<https://dpac.uk.net/2019/02/motion-national-independent-living-support-service/>> accessed 19 February 2019.

¹⁵⁸ ROFA (n149).

¹⁵⁹ John Pring, 'Equality Watchdog Seeks Legal Advice on Possible Right to Independent Living' (*Disability News Service*, 30 November 2017) <<https://www.disabilitynewsservice.com/equality-watchdog-seeks-legal-advice-on-possible-right-to-independent-living/>> accessed 28 May 2018.

describe our aspirations as disabled people'.¹⁶⁰ Morris's suggestion is not that the *principles* of independent living should be rejected, but that they should be re-framed in terms of human rights. This suggestion has been rejected by others in the movement. ROFA argues that independent living is 'a source of pride that sits at the core of our shared identity' and that to 'stop talking about independent living ... would rob Disabled people of one of the few things we have left to hold on to.'¹⁶¹

In both practical and policy terms therefore, independent living is currently at risk. Independent living remains on the Welsh Government agenda, however, with the Welsh Government document, *A Framework for Action on Independent Living* currently being revised and updated.¹⁶²

5. The connection between independent living and the social model

Independent living is closely linked to the social model of disability, and is commonly considered to be built upon, or to flow from, the principles of the social model. Both concepts challenge the position of disabled people in society by demanding full and equal inclusion and participation; and both argue that the reasons for exclusion lie not in the individual's impairment but in social responses to it. Jenny Morris describes the connection in the following terms:

Underpinning the concept [of independent living] is the social model of disability – a focus not on the individual and impairment as the problem but on

¹⁶⁰ Jenny Morris, 'Independent Living and the Future of Social Care' (blogpost, 21 February 2018) <<https://jennymorrisnet.blogspot.co.uk/2018/02/independent-living-and-future-of-social.html>> accessed 28 May 2018. Despite this suggestion, Morris has fully backed the ROFA campaign for a 'national independent living service' discussed above. Jenny Morris, 'Broken Promises: Looking Back on "Improving the Life Chances of Disabled People"' (blogpost, 8 March 2019) <<https://jennymorrisnet.blogspot.com/2019/03/broken-promises-looking-back-on.html>> accessed 18 March 2019. John Pring, 'Broken Promises Have Shattered Hopes of Right to Independent Living, says Morris' (*Disability News Service*, 14 March 2019) <<https://www.disabilitynewsservice.com/broken-promises-have-shattered-hopes-of-right-to-independent-living-says-morris/>> accessed 18 March 2019.

¹⁶¹ ROFA (n149).

¹⁶² See Chapters 10 and 12.

the need to address social, economic and environmental barriers. This approach means recognising that it is these barriers, rather than functional impairments, which get in the way of individual autonomy and self-determination....¹⁶³

In Wales, Miranda Evans has suggested that:

...if the Social Model of Disability is the theory then Independent Living is the practice.¹⁶⁴

Effectively, independent living, as the expression of equality of choice, control and opportunity for disabled people, cannot be achieved without the removal of attitudinal, organisational and practical barriers that the social model stipulates. Access and barrier removal are therefore pivotal components of both.

Morris states that definitions of independent living typically contain three elements:

Firstly, an assertion that disabled people should have the same opportunities for choice and control as non-disabled people; secondly a challenge to the usual interpretation of 'independent'; and finally, the aspiration that any assistance required should be controlled by disabled individuals themselves.¹⁶⁵

Elsewhere, Morris has also stated that the independent living movement is based on four assumptions:

- that all human life is of value;
- that anyone, whatever their impairment, is capable of exercising choices;

¹⁶³ Jenny Morris, *Rethinking* (n2) 11.

¹⁶⁴ Miranda Evans, 'A Tool for Equality: Delivering the Social Model of Disability in Wales' in *Disability Wales, 'More than Words / Mwy na Geiriau: The Journal of Disability Wales'* (2007) <http://www.disabilitywales.org/wp-content/uploads/2018/03/More_Than_Words_1_2007-1.pdf> accessed 14 May 2018, 21.

¹⁶⁵ Jenny Morris, 'Independent Living and Community Care: A Disempowering Framework' (2004) 9(5) *Disability & Society* 427, 427.

- that people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives; and
- that disabled people have the right to fully participate in society.¹⁶⁶

Others have stated that the approach of early groups of disabled people to independent living:

...stressed self-determination, choice (where and how to live) and control over support services (who assists, how and when), and the removal of disabling barriers in mainstream society.¹⁶⁷

When these are compared with the core content of the social model, both shared and distinct content can be seen. The recognition of social barriers and the requirement of barrier removal is common to both, as is the right to social participation. However, independent living goes beyond the social model in three aspects: the *explicit* focus on and prioritisation of *individual* self-determination and choice, the demands that any support needed by a person is under their own control; and the introduction of the idea of independence. In this way, independent living builds upon and fleshes out the social model of disability to create a fuller, more detailed picture of what is required for disabled people to live their own equal lives.

Disabled activists have viewed the relationship between the social model and independent living in different ways. Zarb suggests that independent living 'mirrors the essential principles of the social model',¹⁶⁸ while Beresford states that it 'follows from' it.¹⁶⁹ Finkelstein, who had reservations about various aspects of independent

¹⁶⁶ Jenny Morris, *Independent Lives? Community Care and Disabled People* (Macmillan 1993), 21. Morris has credited these four assumptions to BCOOP.

¹⁶⁷ Barnes and Mercer, *Independent Futures* (n21) 33, citing A Brechin, P Liddiard and J Swain (eds) *Handicap in a Social World* (Hodder and Stoughton in association with the Open University 1981) and F Hasler, J Campbell and G Zarb *Direct Routes to Independence: A Guide to Local Authority Implementation and Management of Direct Payments* (Policy Studies Institute 1999).

¹⁶⁸ Gerry Zarb, 'Independent Living and the Road to Inclusion' in C Barnes and G Mercer (eds) *Disability Policy and Practice: Applying the Social Model* (Disability Press 2004), 192.

¹⁶⁹ Peter Beresford, *What Future for Care?* (Joseph Rowntree Foundation, 2008), 10

living, considered independent living to be a *component* of the social model.¹⁷⁰ Essentially, the two narratives overlap, interlock and complement each other, sharing common aims and elements, particularly relating to self-determination, equality, inclusion and participation.

6. Conclusion

This chapter has set out the background and development of independent living. It demonstrates that in the UK the disabled people's movement arose from a desire among disabled activists to challenge their circumstances and negative public attitudes, and developed through the contestation of the nature of disability itself. Disability activism operated on both a theoretical level – particularly through the development of the social model of disability – and the practical level, which led, among other things, to the development of independent living. These two elements were tightly woven together and tackled different aspects of the social deprivation and exclusion faced by disabled people.

¹⁷⁰ Vic Finkelstein, 'The "Social Model of Disability" and the Disability Movement' (unpublished, 2007) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-The-Social-Model-of-Disability-and-the-Disability-Movement.pdf>> accessed 2 January 2017, particularly 6-7.

Chapter 3: Contexts – Devolved Wales

1. Introduction

This chapter provides information on Wales as a devolved nation. It sets out the lobbying context and the form of the disabled people's movement in Wales. In particular, it indicates that there is a distinct identity within the Welsh governance institutions, characterised by a strong focus on communitarian and collective approaches to the public sector. The chapter closes with an outline of the development of policy and legislation on social care and independent living in Wales during and since the devolution process.

2. The devolution process in Wales

Devolution in Wales has been an incremental process, with competence over certain matters ceded from Westminster in a number of stages.¹ The National Assembly for Wales ('the Assembly') was established by the Government of Wales Act 1998, and the first Assembly Members (AMs) elected in 1999.² Initially, the Assembly was a single, effectively executive, body operating on a cabinet and committee basis³ comprising 60 AMs with powers that were broadly in line with those previously held

¹ For a concise overview of the history of devolution in Wales, see information provided by the National Assembly for Wales on its website: 'The History of Welsh Devolution' (NAW, undated) <<http://www.assembly.wales/en/abthome/role-of-assembly-how-it-works/Pages/history-welsh-devolution.aspx>> accessed 27 February 2018.

² This followed a referendum in 1997, which had a small turnout (50.1 per cent) and produced a small majority (50.3 per cent) in favour of devolution. 6,721 votes separated the result. When the turnout is taken into account, only a quarter of the electorate in Wales voted in favour of the establishment of the National Assembly for Wales. Richard Wyn Jones and Roger Scully, *Wales Says Yes: Devolution and the 2011 Welsh Referendum* (University of Wales 2012), 64-66.

³ The Assembly was originally envisaged as a single corporate body operating through a number of committees. This was altered during the passage of the Government of Wales Bill and the model that was initiated was one in which an Executive Committee had responsibility for discharging the devolved functions, with role of the subject committees being that of contributing to the development of policy and secondary legislation and scrutinising the work of the relevant Secretary. Keith Patchett, 'The New Constitutional Architecture' in John Osmond and J Barry Jones (eds) *Birth of Welsh Democracy: The First Term of the National Assembly for Wales* (Institute of Welsh Affairs and the Welsh Governance Centre 2003), 3.

by the Welsh Office.⁴ AMs were responsible for an annual budget of some £8 billion⁵ and had competence to make secondary legislation when authorised to do so by the UK Parliament.

In 2001 the Assembly separated its executive functions as far as was possible under the terms of the 1998 Act and deployed the term ‘Welsh Assembly Government’ (WAG) (later the Welsh Government)⁶ to distinguish the work of the cabinet from that of the wider Assembly.⁷ This separation was formalised in the Government of Wales Act 2006, which also gave the Assembly limited powers to create primary legislation within 20 defined policy fields.⁸ Among these fields were a number relevant to independent living, including health and ‘social welfare’,⁹ employment, education, transport, and housing.¹⁰ In 2011, following a referendum, the Assembly gained full power to enact statute in all of the 20 devolved areas.¹¹

⁴ The Welsh Office is a department of the UK Government that was established in 1964. It originally had responsibility for local government, housing and planning, and gradually gained further responsibilities relating to areas including education and health. Prior to devolution its role was to advise the UK government on matters relevant to Wales (including the impact of intended and actual UK government policy in Wales); and to oversee the implementation of UK government policy in Wales in those areas over which it had responsibility. Its duties included the drafting of secondary legislation in relation to Wales where required under Acts passed by the UK government. See Richard Rawlings, *Delineating Wales: Constitutional, Legal and Administrative Aspects of National Devolution* (University of Wales Press 2003). The current purpose of the Welsh Office is to represent the interests of Wales in relation to constitutional questions and non-devolved matters and to act as a contact between the Welsh Government and Westminster. See, Russell Deacon, ‘Wales in Westminster and Europe’ in Russell Deacon, Alison Denton and Robert Southall (eds), *The Government and Politics of Wales* (Edinburgh University Press 2018), 58-62.

⁵ Elin Royles, *Revitalizing Democracy? Devolution and Civil Society in Wales* (University of Wales Press 2007) 41, citing Rawlings (n4) 7.

⁶ Or ‘Llywodraeth Cymru’. This name change was effectuated by section 4 of the Wales Act 2014.

⁷ Patchett (n3, 4-5) states that the initial separation of governmental functions took place in November 2001, with the Assembly ‘unanimously support[ing] the clearest possible separation between the Assembly Government and the Assembly that was possible under the legislation’ as it then stood. He notes that this separation significantly stretched ‘the elastic of the original statutory model’.

⁸ Under this system, within the 20 fields, the Assembly was able to legislate (in the form of an Assembly Measure) on specific matters very closely defined by a specific Legislative Competence Order or LCO, which had to be approved by the National Assembly for Wales, the Secretary of State for Wales and both Houses of Parliament. The full process for the approval of a Legislative Competence Order can be found at: National Assembly for Wales, ‘Third Assembly (2007-2011): Legislative Competence Orders’ (*NAW*, undated) <<http://www.assembly.wales/en/bus-home/bus-third-assembly/bus-legislation-third-assembly/bus-legislation-guidance-third-assembly/Pages/bus-legislation-guidance-lco.aspx>> accessed 1 March 2018.

⁹ Social welfare incorporated social services and the ‘care of ...vulnerable persons’. Government of Wales Act 2006 Schedule 7, para 15.

¹⁰ Government of Wales Act 2006, Schedule 7. Other fields of particular relevance to disabled people were education and training, transport, housing and local government.

¹¹ The Assembly gained the power to legislate in the form of statute (rather than an Assembly Measure) without first seeking the consent of the UK Parliament following a referendum on this matter in 2011. The power to devolve full legislative capacity in the 20 fields to Wales following a favourable referendum result was contained within the Government of Wales Act 2006 (Sections 103-105). There

The devolution settlement was fundamentally changed by the Wales Act 2017 which shifted the settlement from a ‘conferred powers’ model (in which legislative powers in certain areas are ceded to the Assembly by Westminster) to one of ‘reserved powers’ – in which the Assembly gained control of all areas except those that are expressly retained by the UK Parliament. On implementation, the Assembly also gained control over Assembly elections (including the power to lower the voting age) and its own affairs (including the power to vary the number of AMs);¹² along with greater fiscal powers including partial control of income tax.¹³ As a result of these gradual stages, policy devolution in Wales has been – and continues to be – ‘a moving game’.¹⁴

Despite the gradual assumption of control over various policy areas, the Assembly and the Welsh Government have always operated in a constrained policy and practical environment. They have been required to create policy, take on significant budget responsibilities and deliver outcomes on matters as diverse as health and agriculture whilst building their own identity and navigating high levels of structural change and developments in competence. This has taken place against a political backdrop of narrow or non-existent governmental majorities, a level of governmental instability and – certainly initially – limited popular support.¹⁵ In relation to independent living, policy and legislative control over core matters, such as social

was therefore no need for further legislation to enable this process. Wyn Jones and Scully (n2, 54) describe this peculiar arrangement as ‘a rare, if not unique, example of the principle of built-in obsolescence being extended from the design of household appliances to that of national constitutions’.

¹² For a brief summary see, Office of the Secretary of State for Wales, ‘A New Chapter for Welsh Devolution’ (*Gov.UK*, 31 January 2017) <<https://www.gov.uk/government/news/a-new-chapter-for-welsh-devolution>> accessed 26 February 2018.

¹³ The Wales Act 2014 made provision for a portion of income tax to be devolved, following a favourable referendum result on this issue (sections 8-9). The Wales Act 2017 removed the requirement for a referendum (section 17). From April 2019, the Welsh Government will be able to vary the amount of the devolved element. See: Welsh Government ‘Income Tax’ (*Welsh Government*, 11 September 2017) <<http://gov.wales/funding/fiscal-reform/welsh-taxes/income-tax/?lang=en>> accessed 26 February 2016. Under the Wales Act 2014 a number of other taxes had also been devolved including stamp duty, business rates and landfill tax. New versions of these taxes will be implemented in Wales from April 2018. See, Welsh Government, ‘Welsh Treasury and Fiscal Reform’ (*Welsh Government*, 2 February 2017) <<http://gov.wales/funding/fiscal-reform/?lang=en>> accessed 26 February 2018. The bulk of the Act came into force on 1 April 2018.

¹⁴ Pete Alcock, ‘Devolution or Divergence? UK Third Sector Policy Since 2000’ in Guy Lodge and Katie Schmuecker (eds) *Devolution in Practice 2010* (Institute for Public Policy Research 2010), 269.

¹⁵ Institute of Welsh Affairs, *Time to Deliver: The Third Term and Beyond: Policy Options for Wales* (Institute of Welsh Affairs 2006) 4-8.

care, education, employment and transport, is tempered by the retention at Westminster of power over other, equally important, areas, including discrimination and benefits, human rights, equality and mental capacity. In addition, while the Government and Assembly have control of a significant budget,¹⁶ this is allocated by Westminster with changes calculated by the Barnett formula. This reflects public expenditure and the UK Government's spending priorities in relation to England, although the Welsh Government has the competence to allocate this funding as it chooses.¹⁷ In Wales, therefore, policy is made largely within a framework that is set by Westminster and, to an extent, reflects Westminster priorities.

Currently, therefore, the Assembly and the Welsh Government have extensive, albeit not unrestricted, power to develop policy and legislation that assists or enables the practical implementation of independent living. Should it desire to do so, the Assembly has the power to pass domestic legislation that enshrines a right to independent living – insofar as it relates to devolved matters – for disabled people in Wales. These powers are, however, relatively recent and still evolving.

3. The policy and lobbying context and the voluntary sector in Wales

Article 4(3) of the UNCRPD requires that disabled people are consulted in the development of policy and legislation that affects them – a legal recognition of the longstanding slogan used internationally by disabled people's movements of 'nothing about us without us'.¹⁸ Devolution and the creation of new governance structures created new possibilities for such consultation and the involvement of DPOs in Wales. One of the stated reasons for Welsh devolution was to create a new form of

¹⁶ The Welsh Government has the responsibility for budget and spending proposals, subject to the scrutiny and approval of the National Assembly for Wales. See, Welsh Government, 'Funding' (*Welsh Government*, 15 September 2011) <<http://gov.wales/funding/?lang=en>> accessed 31 August 2017.

¹⁷ Welsh Government, 'Funding' (*Welsh Government*, 15 September 2011) <<http://gov.wales/funding/?lang=en>> accessed 31 August 2017; House of Commons Library, 'The Barnett Formula' (www.parliament.uk, 23 January 2018) <<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7386#fullreport>> accessed 27 February 2018.

¹⁸ This phrase is used by disabled people's movements internationally although its origins are unknown. Charlton states that he first heard it used in relation to disability in South Africa in 1993 by South African activists who had heard it used in Eastern Europe. James Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment* (University of California Press 2000) 3.

politics which would offer citizens greater access, inclusion and participation in political processes.¹⁹ The devolved structures were intended to 'reach to the parts of Welsh society that were not reached by politics'²⁰ and envisaged as a means of revitalising democracy through engagement with civil society.²¹ Royles states that from the earliest days of devolution, most AMs indeed fostered participation and supported strong relationships between civil society and the new Assembly.²²

Certain structures were established to support this vision of inclusive democracy and to enable and support the participation of civil society in democratic processes. The new Assembly was under a legal duty to develop a scheme to support and consult voluntary organisations.²³ This led to the development of the Voluntary Sector Partnership Council (VSPC) involving AMs, representatives from the Wales Council for Voluntary Action (WCVA) and representatives from voluntary organisations, each representing an identified 'voluntary sector category', one of which was disability.²⁴ Royles argues that the initiative was effective in giving civil society organisations access to the work of the Assembly.²⁵ The VSPC continues today under the name Third Sector Partnership Council.²⁶ The strong focus on the voluntary sector

¹⁹ Royles (n5, 2-3) states that the white paper on devolution, *A Voice for Wales*, argued that a devolved Wales would be a more inclusive and participatory democracy. The white paper is: Welsh Office, *A Voice for Wales: The Government's Proposals for a Welsh Assembly* (Cm 3718, 1997).

²⁰ Ralph Fevre, 'Series Editor's Forward' in Royles (n5) ix.

²¹ Paul Chaney, Tom Hall and Andrew Pithouse, 'New Governance – New Democracy?' in Paul Chaney, Tom Hall and Andrew Pithouse (eds), *New Governance – New Democracy?* (University of Wales Press 2001) 3-5.

²² Royles (n5) 42.

²³ This duty was originally created by Section 114 of the Government of Wales Act 1998. It now exists under Section 74 of the Government of Wales Act 2006. Under Section 74, the Welsh Government is required to set out a scheme that states how the Government will promote the interests of voluntary organisations in Wales and how the Welsh Government will support and consult with such organisations. Alcock (n14, 278) cites this as the broadest such scheme across the UK devolution settlements. Royles (n5, 43) states that it was the first such scheme in Europe.

²⁴ WCVA is a coalition of third sector organisations working in fields including disability, age, education, health, children, education and sport. It includes a wide range of organisations as diverse as support groups and museums. See, WCVA at <<https://www.wcva.org.uk/>> accessed 9 March 2018. The VSPC initially comprised 11 AMs, three WCVA representatives and 21 representatives from the voluntary sector. National Assembly for Wales, 'Voluntary Sector Scheme: First Annual Report to 31 March 2001' (NAW, 4 June 2001) <<http://www.assembly.wales/Laid%20Documents/National%20Assembly%20for%20Wales%20Voluntary%20Sector%20Scheme%20First%20Annual%20Report%20-%20LD949-09072001-24267/bus-GUIDE-3B4C3472000B9B8B000065F600000000-English.pdf#search=voluntary%20sector%20scheme>> accessed 1 March 2018.

²⁵ Royles (n5) 46.

²⁶ See, WCVA, 'Third Sector Partnership Council' (WCVA, undated) <<https://www.wcva.org.uk/what-we-do/influencing/third-sector-partnership-council>> accessed 27 February 2018; and Welsh Government, 'Third Sector Partnership Council' (*Welsh Government*, last updated 7 August 2017)

continues in Wales, recently reiterated in the Welsh Government's 2016-2021 national strategy, *Prosperity for All*.²⁷

In addition, the Government of Wales Act 1998 imposed an onerous equality duty on the Assembly. Section 120 of the 1998 Act required the Assembly to 'have due regard to the principle that there should be equality of opportunity for all people'.²⁸ This duty applies to all functions of the Assembly and Welsh Government, and its focus on *equality across all people* has an encompassing quality that is unique in UK devolution legislation.²⁹ Chaney argues that this principle was intended partially as a statement of distinction between the attitudes and approaches of Westminster and a new form of accessible governance in Wales.³⁰

As a result, equality has been a priority for the Assembly from its inception. The equality duty became another area in which the Assembly explicitly worked with voluntary organisations to achieve 'inclusive governance', particularly those working with minority groups.³¹ Disability Wales was one of a number of umbrella or network organisations which received Assembly funding to support its equality work.³² As a result, civil society groups, including disability organisations (and Disability Wales in

<<http://gov.wales/topics/people-and-communities/communities/voluntarysector/partnership/?lang=en>> accessed 27 February 2018. At the time of writing, disability organisations were represented by the Wales Disability Reference Group (WDRG). WDRG is a network of five 'umbrella organisations for the main disability groups in Wales'. These are Disability Wales, Learning Disability Wales, Mind Cymru, Wales Council for Deaf People and Wales Council of the Blind. See Wales Council for Voluntary Action, 'Disability' (WCVA, undated) <<https://www.wcva.org.uk/what-we-do/influencing/third-sector-partnership-council/disability>> accessed 27 February 2018. At the time of writing, the WDRG representative on the Council was Director of Wales Council of the Blind.

²⁷ Welsh Government, 'Prosperity for All: The National Strategy' (*Welsh Government*, 2017)

<<http://gov.wales/newsroom/firstminister/2017/170919-new-national-strategy-for-a-more-prosperous-wales/?lang=en>> accessed 8 March 2018.

²⁸ This duty is now enshrined in section 77 of the Government of Wales Act 2006.

²⁹ David Lambert, 'The Government of Wales Act: An Act for Laws to be Ministered in Wales in Like Form as it is in this Realm?' (1999) 30 *Cambrian Law Review* 60, cited in Paul Chaney, 'Education, Equality and Human Rights: Exploring the Impact of Devolution in the UK', (2011) 31(3) *Critical Social Policy* 431.

³⁰ Paul Chaney, 'New and Unexplored Possibilities – The Welsh Legislature's Statutory Duty to Promote Equality of Opportunity' (2002) 21(1) *Equal Opportunities International* 19-42.

³¹ Royles (n5), 46, citing P Chaney and R Fevre, 'Inclusive Governance and "Minority" Groups: The Role of the Third Sector in Wales' (2001) 12(2) *Voluntas: International Journal of Voluntary and Nonprofit Organizations* 131.

³² Royles (n5) 46, citing P Chaney and R Fevre, 'An Absolute Duty: Equal Opportunities and the National Assembly for Wales, A Study of the Equality Policies of the Welsh Assembly Government and their Implementation' (2002, published online but no longer available).

particular) achieved an unprecedented level of access to the work of the Assembly.³³ In their study of the contact between disability groups and the Assembly in its early years, Betts et al quote a research participant as saying: 'Disability Wales is pushing as hard as it can ... to get into that position that they never have reached before with centralized government'.³⁴ At the time of writing other bodies also existed that provided lobbying opportunities in relation to equality, including the Welsh Government Disability Equality Forum, which has a specific remit to advise on progress in relation to the Welsh Government's *Framework for Action on Independent Living*.³⁵ Under section 149 of the Equality Act 2010, the Welsh Government is also subject to the public sector equality duty, which requires public authorities to eliminate discrimination, advance equality of opportunity and foster good relationships between people who have a 'protected characteristic' and those who do not.³⁶ The Assembly and the Welsh Government are also obliged to work within the European Convention on Human Rights.³⁷

Other opportunities for lobbying were also created on devolution. The Assembly's subject committees – cross-party groups which exist to scrutinise policy, proposed legislation and other ministerial work in particular fields – were from the earliest days

³³ Royles (n5) 46.

³⁴ Sandra Betts, John Borland and Paul Chaney, 'Inclusive Government for Excluded Groups: Women and Disabled People' in Paul Chaney, Tom Hall and Andrew Pithouse (eds), *New Governance – New Democracy* (University of Wales Press 2001) 66.

³⁵ This brings together Welsh Government ministers and officials and representatives from organisations relating to disability. Following the development of the Framework for Action on Independent Living the Forum has a role in advising on implementation. It meets twice a year. See, Welsh Government, 'Disability Equality Forum' (*Welsh Government*, last updated 7 February 2018) <<http://gov.wales/topics/people-and-communities/equality-diversity/rightsequality/disability/disability-equality-advisory-group/?lang=en>> accessed 27 February 2018.

³⁶ The public sector equality duty contains both the general duty, outlined here and specific duties which relate to matters of implementation such as the need for equality impact assessments and annual reporting. The specific duties are different in the devolved nations, and those in Wales are particularly onerous. The 'protected characteristics' under the 2010 Act are: age, sex, gender reassignment, disability, race, pregnancy, sexual orientation and religion or belief. Section 1 of the Equality Act 2010 also includes certain duties on public authorities to consider the reduction of socioeconomic inequality when making strategic decisions, although this is not yet in force in Wales. Hoffman states that at the time of writing the Welsh Government was 'actively considering whether the duty should commence'. Simon Hoffman, 'Human Rights, Equality and Well-being' (Bevan Foundation, February 2019), <<https://www.bevanfoundation.org/publications/human-rights-and-well-being/>> accessed 20 February 2019, 2.

³⁷ Section 108A(2)(e) of the Government of Wales Act 2006 states that any legal provision passed by the National Assembly that is incompatible with the ECHR is outside the Assembly's legal competence and is not law. Section 81 states that the Welsh Government has no power to pass subordinate legislation or otherwise act in a manner that is incompatible with the European Convention on Human Rights.

intended to have a proactive role in policy-making and provide opportunities for civil society groups to exert an influence via contact with the relevant AMs.³⁸ Other, more informal 'cross-party groups' have also been established, in which AMs with an interest in particular matters discuss issues with relevant individuals and organisations. At the time of writing these included groups on disability, autism, learning disability and various matters of particular relevance to disabled people and independent living such as housing and transport.³⁹

Challenges in relation to policy development that have faced the Assembly and Welsh Government since their inception have also offered lobbying opportunities. On the creation of the Assembly, the available civil service was that which had previously been attached to the Welsh Office – a department with limited policy capacity and expertise.⁴⁰ The role of the Welsh Office had been to apply Whitehall policy within Wales, not to create it from scratch,⁴¹ and was therefore essentially administrative.⁴² In addition, civil servants (and Ministers) in the former Welsh Office had typically been disinclined to consider distinctive policy in Wales.⁴³ Both AMs and civil servants⁴⁴ therefore required knowledge and information to fulfil their roles. These difficulties, along with limited staff support to the Assembly committees,⁴⁵ created opportunities for organisations with particular expertise to provide information and exert influence.

³⁸ Royles (n5).

³⁹ A list of cross party groups, and links to the relevant pages can be found at National Assembly for Wales, 'Cross-Party Groups' (NAW, undated)

<<http://senedd.assembly.wales/mgListOutsideBodiesByCategory.aspx>> accessed 15 July 2018).

⁴⁰ Scott L Greer, 'Health: How Far Can Wales Diverge From England?' in John Osmond (ed), *Second Term Challenge: Can the Welsh Assembly Government Hold Its Course?* (Institute of Welsh Affairs and The Constitution Unit 2003).

⁴¹ Royles (n5).

⁴² Institute of Welsh Affairs, *Time to Deliver: The Third Term and Beyond: Policy Options for Wales* (Institute of Welsh Affairs 2006).

⁴³ John Osmond, 'Introduction' in John Osmond (ed), *The National Assembly Agenda* (Institute of Welsh Affairs 1998).

⁴⁴ Royles (n5).

⁴⁵ These included subject committees and regional committees. Subject committees were originally envisaged as powerful units that would drive the work of the National Assembly. Royles (n5) 42, citing John Osmond, *The National Assembly Agenda* (Institute of Welsh Affairs 1998) and Ron Davies, quoted in M Laffin and A Thomas, 'Designing the National Assembly for Wales' (2000) 53 *Parliamentary Affairs* 557. The regional committees 'were viewed as having the potential to facilitate the interaction of civil society organizations from different areas of Wales with the National Assembly'. Royles (n5) 43.

4. The disabled people's movement in Wales

Most prominent figures and DPOs (including CILs) within the UK disabled people's movement have historically worked and been based in England.⁴⁶ These have included the majority of the key theorists and academics of the movement. During and following devolution, the majority of these commented on the English (or, where relevant, UK) context, with little, if any, noticeable interruption.⁴⁷ Devolution therefore required disabled people in Wales to develop lobbying capacity and expertise.

The rise of a specifically Welsh disabled people's movement is less clearly connected with grassroots activism than the Anglo-British movement. In 1972, at around the same time that UPIAS was emerging, the Wales Council *for the Disabled* (emphasis added) was formed, partially as the result of government intervention and initially as a committee of the Council for Social Services in Wales. Disability Wales states that the inspiration for the Council was a recognition by the Welsh Office that a national voluntary body was needed to speak on behalf of disabled people.⁴⁸ In 1976, the Council became an autonomous organisation, which changed its name to Disability Wales in 1994. It was in 2003 that members of Disability Wales voted to become an organisation run by disabled people and formally to adopt the social model of disability.⁴⁹ What has since become the largest DPO and pan-disability organisation in Wales was therefore initially established on non-DPO lines, in some measure as a result of governmental initiative.

Betts et al provide an assessment of the development of a disability lobby in the early days of Welsh devolution. They note that by September 1999, while some twenty organisations had appointed individuals to engage with the new Assembly, 'only four of these represented disability interests',⁵⁰ and imply that, with the

⁴⁶ Commentators such as Barnes, Oliver, Beresford, Evans and many others fall into this group. In addition, with the exception of Disability Wales, Dewis Centre for Independent living and the former Cardiff and Vale Coalition of Disabled People, the better-established DPOs are in England.

⁴⁷ See Chapter 2, section 2.

⁴⁸ Disability Wales, 'History' (*Disability Wales*, undated) <<http://www.disabilitywales.org/about-us/history/>> accessed 28 February 2018. The Council was originally formed as a committee of the Council for Social Service in Wales.

⁴⁹ *Ibid.* It is worth noting that this was after the Welsh Government formally adopted the social model of disability. See Chapter 2, section 3.

⁵⁰ Betts, Borland and Chaney (n34), 68.

exception of Disability Wales, this capacity was created within the large national non-DPO organisations, rather than organisations made up of disabled people. They argue that while the development of an effective disability lobby was necessary, it was by no means inevitable. Among the requirements discussed for the development of such a lobby were the need for disability organisations to focus on matters identified by disabled people themselves, the need to mobilise disabled people, the need to establish effective campaigning strategies and, most importantly, the need to transfer leadership to disabled people.⁵¹ This discussion suggests that the disability lobby in Wales at that time consisted mostly of ‘establishment’ organisations and that the core principle of action and representation *by*, rather than *of*, disabled people, had not yet become entrenched in Wales.

In the early years of devolution, it is therefore fair to say that the identity of the disabled people’s movement in Wales as one of grassroots activism was less developed than in the Anglo-British context – a finding that is echoed in other research.⁵² This may have been partially a result of a less vibrant civil society in Wales in general.⁵³ However, at their time of writing (2001) Betts et al noted that two DPOs – Disability Wales and Cardiff and Vale Coalition of Disabled People – had become ‘fully engrossed’ with the new forms of consultation in Wales.⁵⁴ Disability Wales in particular seems to have sought to establish a distinctive lobbying identity from the outset. While smaller disability-focused organisations gained a lobbying presence through the WCVA, Disability Wales initially lobbied separately from this coalition.⁵⁵

⁵¹ Ibid 73-75.

⁵² Priestley and others found that disability activism in relation to direct payments was significantly lower in Wales (and Northern Ireland) than in England and Scotland. Mark Priestly and others, ‘Direct Payments and Disabled People in the UK: Supply, Demand and Devolution’ (2007) 37 *British Journal of Social Work* 1189.

⁵³ Royles (n5) suggests that, at the time of devolution, civil society in Wales was weak when compared with other parts of the UK. In 2010 Alcock suggested that a relatively large proportion of Welsh third sector organisations remained made up of small local groups relying on volunteer workers rather than larger national organisations (which tend to have greater lobbying capacity). Alcock (n14) citing G Day, ‘The Independence of the Voluntary Sector in Wales’ in M Smerdon (ed), *The First Principle of Voluntary Action: Essays on the Independence of the Voluntary Sector in Canada, England, Germany, Northern Ireland, Scotland, United States of America and Wales* (The Baring Foundation 2009). This may indicate a relatively fragile civil society across the board in Wales.

⁵⁴ Betts, Borland and Chaney (n34) 75.

⁵⁵ Betts, Borland and Chaney (n34). Disability Wales now lobbies with the WCVA.

The disabled people's movement in Wales remains relatively small in terms of numbers of organisations and their lobbying capacity. Many local and national disability-focused organisations exist, including various Welsh partners of large UK-based non-DPO charities,⁵⁶ although few of these identify as being run by disabled people.⁵⁷ At the time of writing, two centres for independent living (CILs) existed, with two further in early development.⁵⁸ There were also a number of People First organisations – self-advocacy groups run by and for people with learning disabilities,⁵⁹ and some small but active campaigning groups,⁶⁰ and individuals.⁶¹ Larger organisations included All Wales People First, Dewis Centre for Independent Living,⁶² the mental health organisation Hafal,⁶³ and Diverse Cymru⁶⁴ – an equality-focused organisation formed from the 2011 merger of the Cardiff and Vale Coalition of Disabled People and Awetu, which focused on mental health in black and minority ethnic communities. Both Dewis CIL and Diverse Cymru provide a support service

⁵⁶ For example, Mencap Cymru, National Autistic Society Cymru, RNIB Cymru, Action on Hearing Loss Cymru and various others.

⁵⁷ In 2016 the WCVA listed 1440 third sector organisations classified as disability-related (out of 32,555 organisations in total). Welsh Council for Voluntary Action, 'All Wales Database of Voluntary Organisations in Wales, January 2016' (WCVA, undated) available at <<https://www.wcva.org.uk/what-we-do/research>> accessed 28 February 2018.

⁵⁸ John Pring, 'Project Set to Double Number of Independent Living Centres in Wales' (*Disability News Service*, 13 October 2016) <<http://www.disabilitynewsservice.com/project-set-to-double-number-of-independent-living-centres-in-wales/>> accessed 14 October 2016. At the time of writing CILs in Wales included the Dewis Centre for Independent Living <<http://www.dewiscil.org.uk/>> accessed 30 December 2016, the CIL de Gwynedd <<http://www.cildegwynedd.co.uk/>> accessed 30 December 2016; and the FDF Centre for Independent Living (launched on 1 March 2017 and formerly the Flintshire Disability Forum) <<http://www.thefdf.org.uk/>> accessed 8 March 2018. Diverse Cymru was a broader organisation, but had its roots in DPO activity. In addition, there was also a less formal organisation named Swansea Association for Independent Living <<http://sail-swansea.org.uk/>> accessed 18 May 2017.

⁵⁹ The umbrella group, All Wales People First, is at <<http://allwalespeople1st.co.uk/>> accessed 8 March 2018.

⁶⁰ These included a number of the People First organisations and organisations such as Bridgend Coalition of Disabled People, which at the time of writing had an active Facebook page but no website of its own. See Bridgend Coalition of Disabled People (*Facebook*, undated) <<https://en-gb.facebook.com/Bridgend-Coalition-of-Disabled-People-124600127554451/>> accessed 15 July 2019.

⁶¹ At the time of writing the campaign against the abolition of the Welsh Independent Living Grant, which was having significant success, was being undertaken by a small group of individuals, in particular Nathan Lee Davies. See Nathan Lee Davies '#savewilgcampaign' (blogpost, undated) <<https://nathanleedavies.wordpress.com/save-wilg-campaign/>> accessed 6 May 2019. See Chapter 2, section 4 including note 152.

⁶² Dewis CIL was established on DPO principles in 1996 and became a CIL in 2001. See Dewis Centre for Independent Living, 'About' (*Dewis CIL*, undated) <<http://www.disabilitywales.org/about-us/history/>> accessed 28 February 2018. 'Dewis' means 'choice' in Welsh.

⁶³ Hafal describes itself as: 'an organisation managed by the people we support: individuals whose lives have been affected by serious mental illness'. Hafal, 'Home' (*Hafal*, undated) <<http://www.hafal.org/>> accessed 15 July 2019.

⁶⁴ Diverse Cymru, 'Diverse Cymru' (undated) <<https://www.diversesecymru.org.uk/>> accessed 27 July 2019.

for people who use direct payments and employ personal assistants and have responded to Welsh Government consultations. The largest and most prominent DPO remained Disability Wales / Anabledd Cymru. This national umbrella organisation draws together a number of partner organisations in Wales. While not all of these are DPOs, Disability Wales itself is now run by disabled people⁶⁵ and describes its core role as 'provid[ing] a strong voice and leadership to influence policy on the issues that matter to our members'.⁶⁶

In terms of lobbying there is a level of historical and ongoing reliance on the work of Disability Wales. This reliance raises issues both of plurality of the disabled 'voice' in Wales and of independence, as Disability Wales is largely reliant on funding from the Welsh Government.⁶⁷ In the context of this thesis, it is of particular note that its former position of independent living policy officer was funded by the Welsh

⁶⁵ Disability Wales has formerly stated that members of its Board of Trustees must be disabled people. Disability Wales, 'About Us' (n64). This statement no longer appears on its website, but all its current Trustees identify as disabled people. Disability Wales, 'Board Members' (undated) <<http://www.disabilitywales.org/about/board-members/>> accessed 15 July 2019. Disability Wales formerly described itself as: 'a membership organisation of disability groups and allies from across Wales', with 'allies' described as organisations that work in the field of disability or connected areas but which are not themselves DPOs - Disability Wales, 'About Us' (undated) <<http://www.disabilitywales.org/about-us/>> accessed 8 March 2018. (Webpage no longer available.) The current membership of Disability Wales (excluding individuals) can be found at Disability Wales, 'Members List' (undated) < <http://www.disabilitywales.org/about/members/>> accessed 18 July 2019. A similar membership is held by Disability Rights UK, which is the equivalent group in the UK/England context. Disability Rights UK, 'Member Organisations' (undated) <<https://www.disabilityrightsuk.org/membership/member-organisations>> accessed 15 July 2019.

⁶⁶ Disability Wales, 'About' (*Disability Wales*, undated) <<http://www.disabilitywales.org/about/>> accessed 15 July 2019. The formerly stated aim was, 'reflect[ing] the views of disabled people's organisations to government with the aim of informing and influencing policy'. Disability Wales, 'Aims and Objectives' (*Disability Wales*, undated) <<http://www.disabilitywales.org/about-us/aims-and-objectives/>> accessed 28 February 2018 (page no longer available).

⁶⁷ At the time of writing, Disability Wales stated on its website, 'Our core funding is from the Welsh Government Equality and Inclusion Grant which allows our work to continue until 2020. This grant is on a three-year basis. Disability Wales runs a number of projects which have a range of funders, including Big Lottery and the Fawcett Society, Spirit of 2012'. Disability Wales, 'About' (n66). See also, annual reviews for earlier years, such as: Disability Wales / Anabledd Cymru 'Review 2015/2016' (Disability Wales, undated) <<http://www.disabilitywales.org/wp-content/uploads/2019/05/DW-Annual-Review-2016.pdf>> accessed 15 July 2019. It is worth noting here that the UN Committee on the Rights of Persons with Disabilities states, among its list of necessary attributes for a DPO, that DPOs are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organizations of which they might be part/members of'. UN Committee on the Rights of Persons with Disabilities, 'General Comment No. 7 on the Participation of Persons with Disabilities, Including Children with Disabilities, through their Representative Organizations, in the Implementation and Monitoring of the Convention' (UN Doc CRPD/C/GC/7, adopted on 9 November 2018) <<https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>> accessed 12 July 2019, para 11(c).

Government.⁶⁸ This feature is by no means unique to DPOs in Wales – in a UK-wide survey of user-led organisations, Barnes and Mercer found that most of the surveyed organisations were linked in some way to local authority or other public sector agencies.⁶⁹ Such connections inevitably require organisations to walk a difficult line between partnership and challenge.⁷⁰

The lack of separation between civil society and government is known to be a particular and general problem in Wales. In 2017, the National Assembly for Wales Research Service questioned whether a widespread reliance on public funds was causing the third sector in Wales to act as ‘another branch of government’.⁷¹ The Service cited the Bevan Foundation, which had stated that:

[Certain] Welsh charities are substantially funded by the Welsh Government too, and the cash inevitably comes with strings.... their agenda is without

⁶⁸ Disability Wales / Anabledd Cymru, ‘Written Evidence Submitted to the Joint Committee on Human Rights (IL 39)’ (27 April 2011). Published in, Joint Committee on Human Rights, ‘Implementation of the Right of Disabled People to Independent Living: Written Evidence’ (2011) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019, 164-169.

⁶⁹ Colin Barnes and Geof Mercer, *Independent Futures: Creating User-Led Disability Services in a Disabling Society* (Policy Press 2006), 80-82. Note that Barnes and Mercer were not looking specifically at funding in this discussion – the examples cited were of establishment or management integration. Funding from state agencies is a common situation, however, and extends to high profile UK-based DPOs. For example, the National Centre for Independent Living was largely funded by the Department of Health. See, Prime Minister’s Strategy Unit and others, ‘Improving the Life Chances of Disabled People’ (TSO 2005), 85. The Disability Rights UK annual report for 2016-2017 indicated that in the year ending 31 March 2017 DRUK received funding from various UK government departments for various projects including supporting policy development. Disability Rights UK, ‘Report and Financial Statements for the Year Ended 31 March 2017’ (*Disability Rights UK*, undated) <<https://www.disabilityrightsuk.org/sites/default/files/pdf/DRUKannualreportandfinalstatement2017.pdf>> accessed 15 July 2019. Other DPOs, in Wales and England, are also largely reliant on state funding. Dewis CIL receives its core funding from the local authorities to which it provides services. See, Dewis CIL, ‘About’ (n62). The most recent annual review for All Wales People First available at the time of writing on the organisation’s website (financial year 2015-2016) indicates that in that year it received core funding from the Welsh Government. All Wales People First, ‘Annual Report April 2015 -March 2016’ (*All Wales People First*, undated)<<http://allwalespeople1st.co.uk/wp-content/uploads/2017/09/Annual-report-2015-2016.pdf>> accessed 28 February 2018.

⁷⁰ In 1995 Barnes wrote: ‘To get too close to the Government is to risk incorporation and end up carrying out their proposals rather than ours. To move too far away is to risk marginalisation and eventual demise’. Colin Barnes, ‘Disability Rights: Rhetoric and Reality in the UK’ (1995) 10(1) *Disability & Society* 111, 115. It is noted in Chapter 2 (fn 89) that Barnes and Oliver refer to such organisations as ‘semi-independent organizations or quangos’ and consider these detrimental to the disabled people’s movement.

⁷¹ Hannah Johnson, ‘The Welsh Third Sector: An Independent Force or “Just Another Branch of Government”?’ (*National Assembly for Wales Research Service*, 23 June 2017) <<https://seneddresearch.blog/2017/06/23/the-welsh-third-sector-an-independent-force-or-just-another-branch-of-government/>> accessed 25 September 2018.

question set by government. These bodies are arguably the 21st century quango state.⁷²

The Bevan Foundation argued that this position enables funders to ‘frame the problems they are willing to solve’ and ‘determine the outcomes that are acceptable’.⁷³ This discussion did not relate to disability organisations, but suggestions that this problem affects the campaigning agenda and power of Disability Wales have been raised.⁷⁴ The point here is not that Disability Wales and other DPOs are not capable of accurately representing the views of disabled people or influencing Welsh Government priorities and outcomes, but that the documentary output of all these actors must be assessed in the light of this relationship and the ability of the Welsh Government to control the agenda.

If it is true (as Beresford suggests) that ‘movements are only ever as strong as their local grassroots organisations’,⁷⁵ it would appear that the disabled people’s movement in Wales remains relatively weak and less developed in comparison to its Anglo-British counterpart. However, it has had influence. It is noted in Chapter 2 that the social model of disability was adopted by the Welsh Government in 2002 and that the 2010-11 ‘Independent Living NOW!’ campaign led by Disability Wales was at least partially responsible for the decision of the Welsh Government to develop its

⁷² Victoria Winckler, ‘Who Sets the Third Sector Agenda?’ (*Bevan Foundation*, 30 January 2017) <<https://www.bevanfoundation.org/commentary/wales-third-sector-agenda/>> accessed 25 September 2018.

⁷³ Ibid. Similarly, the lobbyist Daran Hill, also cited by the Research Service, stated that: “there is a relationship of co-dependency between many parts of the third sector and the Welsh Government. It sometimes feels that whole swathes of the sector have been almost nationalised and therefore, in effect, muzzled.” Daran Hill, ‘Lobbyists Need to be Transparent Too’ (*Click on Wales*, 10 March 2016) <<http://www.iwa.wales/click/2016/03/lobbyists-need-to-be-transparent-too/>> accessed 15 September 2018.

⁷⁴ Nathan Lee Davis, who at the time of writing was campaigning to save the Welsh Independent Living Grant, has argued that Disability Wales has not supported his campaign as ‘they do not wish to upset their funders’. Nathan Lee Davies, ‘Silenced by Disability Wales’ (blogpost, undated) <<https://nathanleedavies.wordpress.com/2017/10/10/silenced-by-disability-wales/>> accessed 25 September 2018. Disability Wales has stated that it supports the aims of the campaign, but was unable to support a campaign petition as it ‘was too party political’. John Pring, ‘Disabled Activist “Is Fighting for his Life” as he Hands Petition to Welsh Government’ (*Disability News Service*, 21 September 2017) <<https://www.disabilitynewsservice.com/disabled-activist-is-fighting-for-his-life-as-he-hands-petition-to-welsh-government/>> accessed 25 September 2017.

⁷⁵ Peter Beresford, ‘Identity Crisis’ *The Guardian* (London, 29 November 2006) <<https://www.theguardian.com/society/2006/nov/29/socialcare.guardiansocietysupplement>> accessed 8 March 2018.

*Framework for Action on Independent Living*⁷⁶ (see section 6.2 below). All Wales People First has representatives on the Learning Disability Advisory Group to the Assembly,⁷⁷ and contributed the preface to the Welsh Government's 2007 *Statement on Policy and Practice for Adults with a Learning Disability*.⁷⁸ At the time of writing, Disability Wales had recently worked with Disability Rights UK to present evidence to the investigation by the UN Committee on the Rights of Persons with Disabilities on the UK Government's record on delivering disabled people's human rights⁷⁹ – an investigation that came to scathing conclusions.⁸⁰

5. Politics and ideology in the Welsh Government

Wales is a country with a socio-economic, political and cultural identity of its own, the roots of which long pre-date any form of institutional devolution. It has a strong tradition of union membership, collectivism and mutuality,⁸¹ and these traditions have extended into the political arena. Davies suggests that it is 'perhaps no coincidence that Nye Bevan and Jim Griffiths, the two politicians with the greatest responsibility for the modern welfare state, represented Welsh constituencies'.⁸² One of Bevan's inspirations for the modern National Health Service was the model of mutual

⁷⁶ Welsh Government, 'Framework for Action on Independent Living' (Welsh Government, 2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018.

⁷⁷ National Assembly for Wales Learning Disability Advisory Group, 'Fulfilling the Promises: Proposals for a Framework for Services for People with Learning Disabilities' (NAW, June 2001) <<http://www.assembly.wales/Laid%20Documents/The%20Learning%20Disability%20Advisory%20Group.%20Report%20to%20the%20National%20Assembly%20for%20Wales%20Fulfilling%20the%20Promises.%20Propo-17102001-24340/bus-GUIDE-3BD5365D0001C81F0000500700000000-English.pdf>> accessed 6 March 2018.

⁷⁸ Welsh Assembly Government, 'Statement on Policy & Practice for Adults with a Learning Disability' (WAG, March 2007) <<http://gov.wales/docs/dhss/publications/100126policyen.pdf>> accessed 23 February 2018. This document was one of those examined in this study.

⁷⁹ Disability Rights UK and Disability Wales, 'Implementation of the United Nations Convention on the Rights of Persons with Disabilities in England and Wales: Shadow Report' (January 2017) <<https://www.disabilityrightsuk.org/sites/default/files/pdf/CRPD%20shadow%20report%20-%20England%20Wales%2026%20January%202017.pdf>> accessed 12 July 2019.

⁸⁰ John Pring, 'UK Faces UN Examination: Government Cuts Caused 'Human Catastrophe'' (*Disability News Service*, 24 August 2017) <<https://www.disabilitynewsservice.com/uk-faces-un-examination-government-cuts-caused-human-catastrophe/>> accessed 29 August 2017.

⁸¹ Steve Davies, 'The New Politics of Public Services in Wales' in John Osmond (ed) *Second Term Challenge: Can the Welsh Assembly Government Hold Its Course?* (Institute of Welsh Affairs and The Constitution Unit 2003).

⁸² *Ibid* 18. Davies also notes that the school meals project started in Wales.

societies that existed particularly in the mining communities of South Wales.⁸³ Given this history, it is perhaps no surprise that the Labour Party has historically dominated the Welsh political landscape.⁸⁴ Since devolution, Welsh Labour has been the main political force of the Assembly, forming all of its governments to date, albeit sometimes in the minority or in coalition. This one-party dominance is so pronounced that Wyn Jones and Scully argue that it has impacted directly on the construction of the Welsh constitution, with devolution initiatives and processes often aimed at bridging internal Labour Party divides rather than establishing effective governmental structures.⁸⁵

From the early days of the Assembly and the birth of the Welsh (Assembly) Government, Welsh Labour has been keen to develop policy – particularly in relation to public services – that bears its own ideological stamp and reflects this Welsh social and political tradition.⁸⁶ While there was initially limited divergence from Westminster in certain policy areas – including social care – the Welsh Government swiftly began to indicate a desire for a distinct approach to public sector provision.⁸⁷ Broadly speaking, the aim was to pull back from the market and mixed economy models that had dominated Westminster politics since the 1970s and to generate a more universalist and collectivist approach.

Initially, this narrative was developed against a background of Labour administrations in Westminster – devolution was a Labour government initiative and for the first 13 years of a devolved Wales, Labour was in control of both the Westminster and Welsh political institutions. Rhodri Morgan – First Minister of Wales

⁸³ Steven Thompson, 'Welsh History Month: Tredegar, Birthplace of the NHS' (*Wales Online*, 27 March 2013) <<https://www.walesonline.co.uk/news/wales-news/welsh-history-month-tredegar-birthplace-2047332>> accessed 15 February 2019; Steve Thompson, 'NHS Was Not Solely Modelled on a Welsh Workmen's Medical Society' (*The Conversation*, 3 July 2018) <<https://theconversation.com/nhs-was-not-solely-modelled-on-a-welsh-workmens-medical-society-98024>> accessed 15 February 2019.

⁸⁴ Stead provides a brief history of the development of a political 'hegemony' in Wales, including the shift from Liberal to Labour in the first half of the twentieth century. Peter Stead, 'Progressivism and Consensus' in John Osbourne (ed), *Unpacking the Progressive Consensus* (Institute of Welsh Affairs 2008) <<https://www.iwa.wales/wp-content/uploads/2016/04/progconsensustext.pdf>> accessed 15 July 2019.

⁸⁵ Wyn Jones and Scully (n2, 56) also argue that for this reason the devolution process in Wales has been 'deeply flawed' and that compromises for the sake of Labour Party unity 'have been placed at a higher premium than adherence to basic constitutional principles'.

⁸⁶ Davies (n81).

⁸⁷ *Ibid.*

between 2000 and 2009 – described the development of a distinct Welsh Labour identity as putting ‘clear red water’ between the Labour administrations in Cardiff and Westminster.⁸⁸ Davies argues that while the Welsh Government was keen to smooth over any suggestion of a rift between the two Labour administrations – presenting the Welsh distinction as ‘Welsh solutions to Welsh problems’ –⁸⁹ there was a fundamental difference between their underpinning ideologies. In his words:

While Tony Blair stresses the role of the market, praises the efficiency of the private sector and emphasises consumer choice and the market, the language of Labour politicians in Wales is more likely to refer to citizenship, equality of outcome, universality, collaboration rather than competition, and public rather than private provision.⁹⁰

Under the Welsh Labour / Plaid Cymru coalition of the Third Assembly (2007-2011), the governing parties set out a ‘progressive consensus’, the core principles of which were later described as a philosophy of ‘progressive universalism’. The central idea of progressive universalism was that all people should have the same entitlements to public services, that these should be – as far as possible – free at the point of use, and that ‘additional help’ should be available for those who need it most’.⁹¹

Progressive universalism was based on six principles, outlined most notably by Mark Drakeford.⁹² These principles were that:

⁸⁸ The identity of the person who coined this term is not conclusively evidenced, although the *Financial Times* credits it to Mark Drakeford. Jim Pickard, ‘Mark Drakeford Tipped for Labour’s Next Leader in Wales’ *Financial Times* (London, 28 May 2018) <<https://www.ft.com/content/1c1a5b9a-6002-11e8-9334-2218e7146b04>> accessed 6 May 2019. The phrase was famously used by Morgan in a speech at the University of Swansea in December 2002. BBC News, ‘New Labour “Attack” Under Fire’ (*BBC*, 11 December 2002) <<http://news.bbc.co.uk/1/hi/wales/2565859.stm>> accessed 6 May 2019.

⁸⁹ Davies (n81) 19.

⁹⁰ *Ibid* 10.

⁹¹ There is a summary of the principles of progressive universalism in the National Assembly for Wales Research Service document, ‘Key Issues for the Fourth Assembly’ (*NAW Research Service* 2011), available at <<http://www.assembly.wales/NAfW%20Documents/11-026.pdf%20-%2020102011/11-026-English.pdf>> accessed 15 July 2019.

⁹² Drakeford has had a strong influence on the development of Welsh Government policy, particularly in the fields of health and social care, since the early days of devolution. Between 2000 and 2010 he advised the then First Minister, Rhodri Morgan, on health and social policy. Following his election as an AM in May 2011, he was appointed Minister for Health and Social Services in March 2013, Cabinet Secretary for Finance and Local Government in May 2016, and Cabinet Secretary for Finance in November 2017. See, Welsh Government, ‘Rt Hon Mark Drakeford AM’ (undated) <<https://gov.wales/rt-hon-mark-drakeford-am>> accessed 24 July 2019. Drakeford had also repudiated

- government is the best vehicle for achieving social improvement;
- services should be universal rather than means-tested;
- co-operation is better than competition in the design, delivery and improvement of public services;
- policy should be guided by the collective voice of civil society institutions rather than by individual choice;
- the delivery and receipt of public services should be a collaborative rather than a quasi-commercial transaction;
- the purpose of public service provision is equality of outcome rather than equality of opportunity.⁹³

The language of progressive universalism is no longer prevalent at Cardiff,⁹⁴ but the principles formed the underpinning ideology of the Welsh Government at the time of the development of the majority of the Welsh Government policy documents examined in this thesis, including the white paper prior to the 2014 legislation on social care.⁹⁵ The principles of progressive universalism also formed the general policy background to the development of the 2013 *Framework for Action on Independent Living*.⁹⁶

the privatisation and marketisation of the welfare state in his previous career as an academic. See, for example, Ian Butler and Mark Drakeford, 'Which Blair Project? Communitarianism, Social Authoritarianism and Social Work' (2001) 1(1) *Journal of Social Work* 7.

⁹³ Mark Drakeford, 'Progressive Universalism', originally published in Institute of Welsh Affairs, 'Agenda' (Winter 2006-2007) and reproduced in, John Osbourne (ed), *Unpacking the Progressive Consensus* (Institute of Welsh Affairs 2008) <<https://www.iwa.wales/wp-content/uploads/2016/04/progconsensustext.pdf>> accessed 15 July 2019. See also, Mark Drakeford, 'Wales and a Third Term of New Labour: Devolution and the Development of Difference' (2005) 25(4) *Critical Social Policy* 497.

⁹⁴ While the National Assembly for Wales Research Service document 'Key Issues for the Fourth Assembly' (2012) (n91) discusses progressive universalism at some length, the term is missing from the parallel document produced at the start of the Fifth Assembly. National Assembly for Wales Research Service, 'Key Issues for the Fifth Assembly' (*NAW Research Service* 2016) <<http://www.assembly.wales/research%20documents/key%20issues%20-%20english/key%20issues%20-%20english-linked.pdf>> accessed 20 September 2017.

⁹⁵ Welsh Assembly Government, 'Sustainable Social Services for Wales: A Framework for Action' (2011) <<http://gov.wales/docs/dhss/publications/110216frameworken.pdf>> accessed 9 March 2018.

⁹⁶ Mark Drakeford, 'Wales in the Age of Austerity' (2012) 32(3) *Critical Social Policy* 454, 461-462.

In this thesis, this set of political principles is termed the ‘Welsh Government communitarian narrative’.⁹⁷ It is a remarkable departure from the political ideologies that have dominated politics in the UK and beyond since the late 1970s. It is outside the scope of this thesis to provide an analysis of Westminster politics over this period, although certain principles need to be summarised for contextual purposes. It is widely recognised that the Thatcher administrations, which began in 1979, introduced a series of socio-economic principles typically characterised as neoliberal.⁹⁸ That term is widely used and applied to multiple ideas,⁹⁹ but there is a general consensus around certain broad principles. These include the supremacy of the free market in the international, private and state sectors,¹⁰⁰ and the reification of the role and freedom of the private individual.¹⁰¹ In relation to the welfare state, the dominant principles are the privatisation and marketisation of public sector support;¹⁰² and the obligation of the individual to maximise their self-sufficiency, minimise their need for state assistance and to accept responsibilities in return for rights.¹⁰³ Garrow and Hasenfeld argue that the ‘moral underpinnings’ of neoliberalism are ‘individual liberty, the virtue of competition, individual responsibility and the work ethic’.¹⁰⁴

⁹⁷ Osmond suggests that it was at this point that the Welsh Assembly Government began firmly to establish a policy identity that was distinct from the Labour administrations in Westminster. John Osmond, ‘Introduction’ in John Osmond (ed), *Second Term Challenge* (Institute of Welsh Affairs and The Constitution Unit 2003). Rhodri Morgan’s ‘Clear Red Water’ speech, outlining the intention to build policy on principles that were distinct from those of New Labour, was given on 11 December 2002. See John Osmond, ‘Making the “Red Water” Really Clear’ (*Institute of Welsh Affairs*, 9 July 2010) <<http://www.iwa.wales/click/2010/07/making-the-%E2%80%98red-water%E2%80%99-really-clear/>> accessed 1 March 2018. An unauthenticated copy of the speech is available on the website of the Socialist Health Association. See, Rhodri Morgan, ‘Clear Red Water’ (speech to the National Centre for Public Policy, Swansea University, 11 December 2002) (*Socialist Health Association*, undated) <<https://www.sochealth.co.uk/the-socialist-health-association/sha-country-and-branch-organisation/sha-wales/clear-red-water/>> accessed 1 March 2018.

⁹⁸ It is frequently asserted that ‘Neoliberalism as a political ideology had its genesis in the 1970s and early 1980s when Thatcher and Reagan came to power in the UK and the US’. See, for example, Yvonne Hartman, ‘In Bed with the Enemy: Some Ideas on the Connections between Neoliberalism and the Welfare State’ (2005) 53(1) *Current Sociology* 57.

⁹⁹ *Ibid*; Hanne Marlene Dahl, ‘Neo-liberalism Meets the Nordic Welfare State – Gaps and Silences’ (2012) 20(4) *Nordic Journal of Feminist and Gender Research* 283.

¹⁰⁰ Hartman (n98). Basak Kus, ‘Neoliberalism, Institutional Change and the Welfare State’ (2006) 47(6) *International Journal of Comparative Sociology*, 488.

¹⁰¹ Hartman (n98). Eve E Garrow and Yeheskel Hasenfeld, ‘Social Enterprises as an Embodiment of a Neoliberal Welfare Logic’ (2014) 58(11) *American Behavioral Scientist* 1475.

¹⁰² Hartman (n98); Garrow and Hasenfeld (n101).

¹⁰³ Garrow and Hasenfeld (n101).

¹⁰⁴ *Ibid* 1478.

In UK welfare state terms, neoliberal principles have replaced principles of collective responsibility, social justice and the redistribution of wealth¹⁰⁵ with a narrative of ‘dependency’ and economic inefficiency.¹⁰⁶ Responsibility is transferred from ‘state to market and from collectivity to individuals’.¹⁰⁷ Subsequent administrations in Westminster have adhered to these broad principles,¹⁰⁸ with the marketisation of public services and the language of ‘no rights without responsibilities’ becoming increasingly entrenched under New Labour.¹⁰⁹

The Welsh Government communitarian narrative pulls against this broad ideology. The principles of progressive universalism argue that responsibility for social welfare lies with governments not markets, that the welfare state holds a redistributive role, and that the public sector should be driven by cooperative and collective rather than competitive and individual forces and should not operate on commercial principles. The content of each of these principles has been challenged,¹¹⁰ and various Welsh Labour politicians have questioned the focus on both the separation from the wider Labour Party and the creation of a ‘Welsh’ political identity.¹¹¹ However, while progressive universalism is no longer specifically cited as the underlying ideology of recent administrations in Wales, the general values of cooperation, collaboration, community and non-commercialism remain at the forefront of the Welsh Government agenda. At the time of writing Mark Drakeford – the architect of progressive universalism – had recently been elected as the leader of Welsh Labour and become the First Minister of Wales.¹¹²

¹⁰⁵ Ibid.

¹⁰⁶ Hartman (n98).

¹⁰⁷ Garrow and Hasenfeld (n101) 1478, citing P Taylor-Gooby (ed), *New Risks, New Welfare: The Transformation of the European Welfare State* (OUP 2004).

¹⁰⁸ Peter Scourfield, ‘Social Care and the Modern Citizen: Client, Consumer, Service User, Manager and Entrepreneur’ (2007) 37 *British Journal of Social Work* 107.

¹⁰⁹ Anthony Giddens, *The Third Way* (Polity Press 1998), cited in Garrow and Hasenfeld (n101). See also Anthony Giddens, *The Third Way and Its Critics* (Polity Press 2000); Martin Powell, ‘New Labour and the Third Way in the British Welfare State: A New and Distinctive Approach?’ (2000) 20 *Critical Social Policy* 39.

¹¹⁰ See, for example, Institute of Welsh Affairs, ‘Unpacking the Progressive Consensus’ (IWA 2008).

¹¹¹ BBC News, ‘Pull Plug on “Red Water” Says MEP’ (*BBC*, 25 September 2007) <<http://news.bbc.co.uk/1/hi/wales/7011770.stm>> accessed 30 October 2018.

¹¹² The previous leader of Welsh Labour was Carwyn Jones, who had held the role and the office of First Minister of Wales since December 2009. Carwyn Jones stood down both roles on 21 April 2018. Nadia Khomami, ‘Carwyn Jones to step down as first minister of Wales’ *The Guardian* (London, 21 April 2018) <<https://www.theguardian.com/politics/2018/apr/21/carwyn-jones-to-step-down-as-first-minister-of-wales>> accessed 25 October 2018. Of the three candidates for these positions, two – Drakeford and Eluned Morgan AM – identified as socialist and on the left wing of the Labour Party.

More recently the Welsh Government has been required to operate within the new and deeply resonant narrative of 'austerity' which has dominated Westminster politics since 2010. Austerity was originally promoted as a response to the international financial crisis of 2008 before becoming an ideology in its own right.¹¹³ It has provided an apparent justification for – and enabled the popular acceptance of – swingeing cuts to the welfare state and the public sector. The New Economics Foundation has argued that the narrative of austerity is underpinned by a number of frames that are resilient to factual analysis and challenge. They include: 'Britain is broke' and in 'dangerous debt' caused by excessive public spending, the existence of 'big bad government' which impedes progress, interferes in people's lives and rewards the undeserving, the existence of 'strivers and skivers' – those who choose to work hard versus those who choose idleness; and the nature of 'welfare as a 'drug' that creates addiction in those who use it.¹¹⁴ The correlation with the principles of neoliberalism outlined above is not coincidental. Austerity has facilitated the promotion of the socio-economic policies based on principles of individual self-sufficiency, the minimisation of the state and the removal of collective responsibility that characterises neoliberal politics,¹¹⁵ creating an increasingly hostile environment for the Welsh Government communitarian narrative.

For the Welsh Government, austerity is less a narrative than a context that has led to a significant reduction in its available resources and within which it is forced to operate. It has refused to adopt the Westminster narrative and has chosen to attempt to retain its communitarian principles in the face of shrinking resources.

The third candidate, Vaughan Gething, was strongly connected to the trade union movement in Wales and backed by the Co-operative Party.

¹¹³ See, for example, two speeches by David Cameron in 2009 and 2013 – one prior to his role as Prime Minister and one during his first administration – both reported in 'The Guardian'. Deborah Summers, 'David Cameron Warns of "New Age of Austerity"' *The Guardian* (London, 26 April 2009) <<https://www.theguardian.com/politics/2009/apr/26/david-cameron-conservative-economic-policy1>> accessed 15 February 2019; Nicholas Watt, 'David Cameron Makes Leaner State a Permanent Goal' *The Guardian* (London, 12 November 2013) <<https://www.theguardian.com/politics/2013/nov/11/david-cameron-policy-shift-leaner-efficient-state>> accessed 15 February 2019. Drakeford (n96) has argued that austerity provided an opportunity for the 2010 coalition government to embrace the shrinking and rolling back of the welfare state.

¹¹⁴ Carys Afoko and Daniel Vockins, *Framing the Economy: The Austerity Story* (New Economics Foundation 2013) <https://neweconomics.org/uploads/files/a12416779f2dd4153c_2hm6ixryj.pdf> accessed 15 July 2019.

¹¹⁵ Iain Ferguson and Michael Lavalette, 'Crisis, Austerity and the Future(s) of Social Work in the UK' (2013) 1(1) *Critical and Radical Social Work*, 95.

Drakeford has argued that it adhered to its principle of protecting universal services – despite civil service advice to do the opposite – as ‘a political decision, based on a set of underpinning beliefs’, and to protect funding to local authorities given their position as ‘the delivery arm of much of the welfare state’.¹¹⁶ The Welsh Government is, however, required to work within and therefore to explain the financial climate. Its documents certainly refer to constraints on its resources, typically presented as an external factual circumstance,¹¹⁷ and sometimes directly attributed to the Westminster government.¹¹⁸

6. The development of policy and law on adult social care and independent living in Wales

The reasons for the focus on social care are set out in Chapter 1.¹¹⁹ In summary, these are that independent living has a historical connection and particular links to social care policy and provision. In addition, the development of major legislation in the field of social care in both Wales and England provided the opportunity for principles of independent living to be enshrined in domestic legislation. This section provides contextual information about policy and legislation on social care and independent living in Wales.

6.1. Policy and law on adult social care

Health and social care have been among the most significant responsibilities for the Assembly since its inception. Poverty and rates of ill health and disability in Wales

¹¹⁶ Drakeford (n96) 457-458.

¹¹⁷ For example, ‘[t]he financial outlook is difficult. We cannot buy a way forward’. Welsh Assembly Government, ‘Sustainable Social Services’ (n95) para 1.10; ‘Furthermore, demand is rising across social services, yet the financial outlook for all public services is difficult.’ Welsh Government, ‘Consultation Document: Social Services (Wales) Bill’ (2012) <<http://gov.wales/docs/dhss/consultation/120312consultationen.pdf>> accessed 23 February 2018, 5.

¹¹⁸ For example, ‘Austerity imposed by the UK Government continues, and every objective analysis of the potential impact of Brexit says we should be prepared for a shrinking economy. ... That is the new reality for this Assembly, and every party must adapt to this if they are to play a serious role in Wales’ future.’ Welsh Government, ‘The Programme for the Fifth Assembly: Taking Wales Forward 2016-2021’ (2016) <<https://gov.wales/sites/default/files/publications/2017-08/taking-wales-forward.pdf>> accessed 15 July 2019, 3.

¹¹⁹ Section 3.

are among the highest in the UK,¹²⁰ and health and social care has historically been the Assembly's area of greatest expenditure.¹²¹ It therefore provides a unique field for the Welsh Government to develop its own policy identity. This is particularly the case given that the social care policy and structures that Wales inherited from Westminster on devolution were driven by the principles of public sector minimisation and marketisation that the Welsh Government has sought to reject. This section provides information on that legacy. As there is a large amount of literature available in relation to the development of social care policy in England, basic information only is provided.¹²²

During the Conservative administrations from 1979 to 1997, social care in England and Wales underwent a process of radical change. Longstay hospitals were closed, there was a focus on establishing 'care in the community' and a mixed economy and market principles were introduced to the care system.¹²³ These developments were driven by both budgetary and ideological concerns, including a desire to reduce the

¹²⁰ In 2016, Wales had one of the highest proportions of disabled people in the UK (26 per cent, compared with 14 per cent in London), Department for Work and Pensions, 'Family Resources Survey 2015/2016' (undated)

<https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/600465/family-resources-survey-2015-16.pdf> accessed 19 September 2017. The National Survey for Wales 2016-2017 states that one in three people reported being limited due to a health problem or disability. See, Welsh Government, 'Statistical Bulletin' (20 September 2017)

<<http://gov.wales/docs/statistics/2017/170920-national-survey-2016-17-illnesses-en.pdf>> accessed 5 March 2018.

¹²¹ For the financial year 1998-1999, the planned combined Welsh Office and local authority expenditure for health and personal social services was £3,158 million, or 42.6 per cent of the total available budget of £7,421 million. Nigel Blewitt, 'Allocating the Budget' in John Osmond (ed), *The National Assembly Agenda: A Handbook for the First Four Years* (Institute of Welsh Affairs 1998) 53. In 2019, spending on the NHS accounted for over half (52.3 per cent) of the Welsh Government's total budget. Senedd Research, 'Devolution 20 – Are We a Healthier Nation?' (*National Assembly for Wales*, 1 May 2019) <<https://seneddresearch.blog/2019/05/01/devolution-20-are-we-a-healthier-nation/>> accessed 9 May 2019.

¹²² For a brief history of social care legislation in the UK and, subsequently, England, see Luke Clements, *Community Care and the Law* (6th edn, Legal Action Group 2017), Introduction. For a study of community care in the light of the experience of disabled people and independent living, see Jenny Morris, *Independent Lives? Community Care and Disabled People* (Macmillan 1993). For recent discussions in adult social care in England see, Iain Ferguson and Michael Lavalette (eds), *Adult Social Care* (Policy Press 2014). For a history of disability policy in the UK see, Anne Borsay, *Disability and Social Policy in Britain since 1750: A History of Exclusion* (Palgrave Macmillan 2005). For a history of the rise of marketisation in UK public services see, John Clarke and others, *Creating Citizen-Consumers: Changing Publics and Changing Public Services* (Sage 2007).

¹²³ The term 'community care' was first used in 1957 by the Royal Commission on Mental Illness and Mental Deficiency. See Borsay (n122) 169. For information on marketisation principles in the welfare state, see: Brian Lund, 'Major, Blair and the Third Way in Social Policy' (2008) 42(1) *Social Policy & Administration* 43.

size of the state and introduce market values to public services.¹²⁴ The 1989 white paper *Caring for People*¹²⁵ and the subsequent National Health Service and Community Care Act 1990, framed older and disabled people as ‘consumers’ of services, and local authorities as buyers rather than providers.¹²⁶ It was during these administrations that the entitlement to receive direct payments – the key delivery tool for independent living pioneered by disabled people – was placed into law for the first time.¹²⁷ While this was a clear success for the disabled people’s movement,¹²⁸ there is little doubt that this success was facilitated by the fact that direct payments convert recipients of social care into purchasers – a transformation that found favour with the then government’s marketisation principles. The closure of longstay hospitals and the reforms wrought by the 1990 Act, which required local authorities to carry out personal assessments for those who might need support, also shifted the focus of social care from the general to the individual, with local authorities now required to organise individual care packages.¹²⁹

Similar reforms continued when ‘New Labour’ gained political power, and the marketisation of public services became more firmly established.¹³⁰ In addition to the promotion of direct payments, a new form of individualised support was conceived, in the form of personal, or individual, budgets.¹³¹ Personal budgets are the allocation of

¹²⁴ Butler and Drakeford (n92).

¹²⁵ Department of Health and Social Security and others, *Caring for People: Community Care in the Next Decade and Beyond* (Cm 849, 1989).

¹²⁶ One of the six key aims of the white paper was the development of ‘a flourishing independent sector’ in social care (para 1.11). During the latter decade of the Conservative’s 18 years in power, a quasi-market was developed in social care as in other sections of the public sector. While funding continued to be provided by the state, services were increasingly provided by (or purchased from) a variety of competing independent suppliers, including charities and commercial businesses. See, Lund (n123).

¹²⁷ The Community Care (Direct Payments) Act 1996 enabled cash in lieu of services to be provided directly to ‘service users’ for the first time. Previously, payments had been made through intermediaries as the provision of cash by local authorities to individuals was prohibited by s29(6)(a) of the National Assistance Act 1948. See John Evans, ‘The Independent Living Movement in the UK’ (*Independent Living Institute* 2003) <<https://www.independentliving.org/docs6/evans2003.html#1>> accessed 6 January 2018, section 2.3.

¹²⁸ *Ibid.*

¹²⁹ Barnes and Mercer (n69).

¹³⁰ K Farnsworth, ‘Capital to the Rescue? New Labour’s Business Solutions to Old Welfare Problems’ (2006) 26(4) *Critical Social Policy* 187, cited in, Mark Baldwin, ‘Social Care under Blair’ in Martin Powell (ed), *Modernising the Welfare State* (Policy Press 2008), 77.

¹³¹ Personal budgets are sometimes also be referred to as ‘individual budgets’ although there is a distinction in these two models. In brief, personal budgets refer to monies that derive from social care funds allocated to local authorities. Individual budgets refer to notional budgets comprised of funding from multiple sources. Following piloting, the notion of individual budgets was dropped. Jenny Morris,

a notional sum of money to an individual to be 'spent' on services.¹³² On their inception, personal budgets were connected to the ideas of the disabled people's movement, presented in particular as a means to enable independent living by extending the benefits of direct payments to wider groups of people.¹³³ Personal budgets certainly had a certain heritage in the ideas of the movement, particularly direct payments, although they were themselves conceived and developed by professionals and non-user controlled organisations.¹³⁴ Under the Care Act 2014 every individual receiving state-funded social care is required to have a personal budget as part of their care plan.¹³⁵

Under the Blair and Brown administrations, direct payments and personal budgets became attached to a philosophy of social care provision known as 'personalisation' – a concept that has been forcefully promoted by all successive administrations.¹³⁶ Like personal budgets, personalisation was presented as having its roots in the ideas of the disabled people's movement and as a means of promoting independent living.¹³⁷ It has, however, a different heritage. Individuals at the think tank Demos, who coined the term 'personalisation' and wrote on this theme also connected it with the marketisation of public services, and a transformation in the delivery and purpose of the welfare state in which responsibility shifts in some measure from the state to the individual.¹³⁸ In the English context, personalisation and the use of personal

'Personal Budgets and Self-Determination' (blogpost, 24 April 2014) <<http://jennymorrisnet.blogspot.co.uk/>> accessed 8 May 2014.

¹³² Unless the personal budget is taken as a direct payment, no actual money is devolved to the individual.

¹³³ See, in particular, 'Improving the Life Chances of Disabled People' in which personalisation was particularly connected with personal budgets, which were in turn presented as a means of expanding the benefits of direct payments to greater numbers of people. Prime Minister's Strategy Unit, 'Improving the Life Chances of Disabled People' (TSO January 2005).

¹³⁴ Peter Beresford, 'Personalisation: From Solution to Problem' in Iain Ferguson and Michael Lavalette (series eds) *Personalisation* (Policy Press 2014).

¹³⁵ Section 25(1)(e).

¹³⁶ Personalisation was first discussed in relation to social care provision in the pivotal 2005 document *Improving the Life Chances of Disabled People* (n133). It was also discussed in Department of Health 'The Case for Change' (HM Government 2008), Department of Health, *Shaping the Future of Care Together* (Cm 7673, 2009), and Department of Health, *Caring for Our Future* (Cm 8378, 2012), among others.

¹³⁷ PMSU (n133).

¹³⁸ This is seen in a trio of documents produced by Demos: Charles Leadbeater, *Personalisation through Participation: A New Script for Public Services* (Demos 2004); Charles Leadbeater, Jamie Bartlett and Niamh Gallagher, *Making It Personal* (Demos 2008); and Jamie Bartlett, *Getting More for Less: Efficiency in the Public Sector* (Demos 2009). A further impact of personalisation in the Demos texts is and a reduction in public spending.

budgets have been cited as a new way forward for the welfare state and a means of remodelling the ‘citizen-state contract’.¹³⁹ In England, social care – in which direct payments and personal budgets were pioneered – has therefore become a testing ground for a further stage in the individualisation of the welfare state. Personal budgets and direct payments have been extended to maternity services,¹⁴⁰ health care¹⁴¹ and education;¹⁴² and may yet extend beyond these fields.¹⁴³ In Wales, the policy of ‘personalisation’ has been rejected owing to its connections with the marketisation of the public sector.¹⁴⁴

Despite this strong connection with ideas that have been historically rejected by the prevailing political ideology in Wales, the Welsh Government did not immediately seek to stamp its own identity on social care policy.¹⁴⁵ It created no major strategy or document on social care specifically, but considered it either in conjunction with

¹³⁹ Simon Duffy, ‘Smart Commissioning: Exploring the Impact of Personalisation on Commissioning’ (*in Control*, 4 February 2008) <<http://www.in-control.org.uk/media/37236/smart%20commissioning%20%20.pdf>> accessed 15 July 2019; Association of Chief Executives of Voluntary Organisations (ACEVO), ‘Making it Personal: A Social Market Revolution: The Interim Report of the ACEVO Commission on Personalisation’ (ACEVO 2009), as cited in Catherine Needham, *Personalising Public Services: Understanding the Personalisation Narrative* (Policy Press 2011).

¹⁴⁰ NHS England, ‘Personal Maternity Care Budgets (PMCBs)’ (undated) <<https://www.england.nhs.uk/mat-transformation/mat-pioneers/questions-and-answers-about-maternity-pioneers/personal-maternity-care-budgets-pmcbs/>> accessed 15 July 2019.

¹⁴¹ Personal budgets have been available to adults with long-term health conditions since 2014. NHS England, ‘NHS Personal Health Budgets (PHBs)’ (undated) <<https://www.england.nhs.uk/healthbudgets/>> accessed 15 July 2019.

¹⁴² Parents of children with special educational needs can now request personal budgets in relation to their children’s educational needs. A local authority is required to identify a personal budget in relation to a child or young person who has an Education, Health and Care Plan, although in certain circumstances the authority can refuse to do so. Department for Education and Department of Health, *Special Educational Needs and Disability Code of Practice: 0-25 Years* (January 2015) at <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf> accessed 15 July 2019.

¹⁴³ In 2008, Demos suggested that personal budgets could also be used to support unemployed people, young people not in employment, education or training and ‘families at risk’. Leadbeater, Bartlett and Gallagher (n138) ch 7.

¹⁴⁴ Welsh Assembly Government, ‘Sustainable Social Services’ (n95) stated, ‘We believe that the label “personalisation” has become too closely associated with a market-led model of consumer choice, but we are taken by the Commission’s approach to stronger citizen control’ (para 3.16).

¹⁴⁵ There were, however, various reviews of social care. These included the ‘Wanless Report’, Welsh Assembly Government, ‘The Review of Health and Social Care in Wales: The Report of the Project Team’ (June 2003) <<http://www.wales.nhs.uk/documents/wanless-review-e.pdf>> accessed 17 October 2018. Other reviews include, The Audit Commission in Wales, ‘Transforming Health and Social Care in Wales: Aligning the Levers of Change’ (April 2004) <<http://www.wales.nhs.uk/documents/HealthSocCareWales.pdf>> accessed 17 October 2018.

health services,¹⁴⁶ or as part of the wider public or social services remit.¹⁴⁷ While there was a promise in the Second Assembly to end home care charges for disabled people, the ‘headline’ public sector policy pledges made by the First and Second Assemblies (elected in 1999 and 2003) contained none others in relation to social care.¹⁴⁸ Guidance for public agencies under relevant legislation tended to diverge in only a limited way from that issued in England.¹⁴⁹ By 2008 there was so little divergence in social care policy and legislation between England and Wales that when the Law Commission began an investigation into social care legislation, the Welsh Assembly Government argued that it should not be a joint funder of the project.¹⁵⁰

This Law Commission investigation brought reform of social care law to the fore in both England and Wales. The Law Commission recommended the replacement of the then existing complex and convoluted legal framework for social care law with a ‘simple, consistent, transparent and modern’ legal framework.¹⁵¹ While the Law Commission initially recommended a single statute applicable in both England and Wales,¹⁵² it revised its view on this following the 2011 referendum in Wales and recommended that the legislative reform of social care should be undertaken by the

¹⁴⁶ For example, Welsh Assembly Government, ‘Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century’ (2005)
<<http://www.wales.nhs.uk/documents/designed%2Dfor%2Dlife%2De%2Epdf>> accessed 23 February 2018.

¹⁴⁷ For example, Welsh Assembly Government, ‘Sustainable Social Services’ (n95). In contrast, the Westminster government has, since 1999, developed at least six single issue white papers or other major strategy documents on adult social care and more are in the pipeline.

¹⁴⁸ Davies (n81).

¹⁴⁹ For example, see the eligibility criteria for the receipt of social care, published by both the Welsh Assembly Government and the Department of Health in 2002. The eligibility criteria were called, in each country, ‘Fair Access to Care Services’. In the Welsh Government this was placed as one chapter in a wider document on the assessment and management of social care, although the content of the eligibility criteria was essentially the same. For the English guidance, see Department of Health, ‘Fair Access to Care Services’ (2002)

<https://webarchive.nationalarchives.gov.uk/20121205180615/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4019641.pdf> accessed 10 May 2019.

For the Welsh guidance see Welsh Assembly Government and NHS Cymru / Wales, ‘Creating a Unified and Fair System for Assessing and Managing Care’ (2002)

<<http://www.wales.nhs.uk/sitesplus/documents/829/WAG%20-%20Creating%20a%20Unified%20and%20Fair%20System%20for%20Assessing%20and%20Managi ng%20Care.PDF>> accessed 10 May 2019. This document and its connection with the English guidance is discussed in Chapter 9.

¹⁵⁰ Law Commission, *Adult Social Care: A Consultation Paper* (Law Com No 192, 2010).

¹⁵¹ *Ibid* paras 1.4-1.5.

¹⁵² *Ibid* para 2.11.

Assembly.¹⁵³ The legislation therefore gave the Welsh Government and the Assembly their first significant opportunity to stamp their own public sector principles on legislation. The resulting statute is discussed in Chapter 11.

Since the 2014 Act, there has been a strong focus on social care in Wales. The Regulation and Inspection of Social Care (Wales) Act 2016 made certain amendments to the delivery of social care¹⁵⁴ and expanded the remit of the regulatory body for social care workers (formerly the Care Council for Wales). The revised body, Social Care Wales, has overall responsibility for leading improvement in the social care sector. It came into effect and launched a five-year strategy in relation to domiciliary support in September 2017.¹⁵⁵ It is also leading a drive to 'professionalise' the social care workforce in Wales, particularly through the registration of social care workers.¹⁵⁶ Social care has had a reasonably protected budget in Wales in comparison to England,¹⁵⁷ and at the time of writing a debate on the future of social care funding was ongoing.¹⁵⁸ In 2016 the Welsh Government

¹⁵³ Law Commission, *Adult Social Care* (Law Com No 326, 2011) para 3.9.

¹⁵⁴ Section 8 of the 2016 Act, for example, outlaws domiciliary care visits of less than 30 minutes, except in certain circumstances.

¹⁵⁵ Social Care Wales, 'Care and Support at Home in Wales: Five Year Strategic Plan 2017-2022' (2017) <https://socialcare.wales/cms_assets/file-uploads/204-0217-SCW-ENG-5-year-strategic-plan-report_v11.pdf> accessed 6 March 2018.

¹⁵⁶ The registration of social care workers in domiciliary settings is required by 2020. Social Care Wales, 'What is Registration?' (undated) <<https://socialcare.wales/registration/what-is-registration#section-33303-anchor>> accessed 18 July 2019. It is currently intended that the registration of workers in care and nursing homes will be required from 2022. Mark Drakeford, 'Written Statement - Registration of Social Care Workers' (*Welsh Government*, 12 November 2015) <<https://gov.wales/written-statement-registration-social-care-workers>> accessed 17 June 2019. Registered social care workers are required to abide by a Code of Practice, published by Social Care Wales, in which social care is consistently referred to as a 'profession'. The Code itself is called 'The Code of Professional Practice for Social Care' (Social Care Wales 2017) <https://socialcare.wales/cms_assets/file-uploads/Code-of-Professional-Practice-for-Social-Care-web-version.pdf> accessed 18 July 2019.

¹⁵⁷ Daria Luchinskaya, Joseph Ogle, and Michael Trickey, 'A Delicate Balance? Health and Social Care Spending in Wales' (Wales Public Services 2025, 2017) <http://www.walespublicservices2025.org.uk/files/2017/03/Wales-health-and-social-care-final_amended_04-2017.pdf> accessed 6 March 2018. See also the announcement in June 2018 by the Social Care Minister, Huw Irranca-Davies, "In Wales, We're Investing in and Prioritising Social Care" (*Welsh Government*, 13 June 2018) <[https://gov.wales/newsroom/health-and-social-services/2018/carew/?lang=en](https://gov.wales/newsroom/health-and-social-services/2018/health-and-social-services/2018/carew/?lang=en)> accessed 17 October 2018.

¹⁵⁸ Debate has centred in particular around the 2018 'Holtham report', commissioned by the Welsh Government, which favoured an increase in income tax to fund social care. Gerald Holtham, 'Paying for Social Care: An Independent Report Commissioned by the Welsh Government' (*Welsh Government*, 2018) <<https://gweddill.gov.wales/docs/caecd/publications/180628-paying-for-social-care-en.pdf>> accessed 10 May 2019. For a round up of the issues, see Senedd Research, 'In Brief: How Should We Pay for Social Care in the Future?' (*National Assembly for Wales*, 7 January 2019)

commissioned a Parliamentary review of health and social care which reported on 16 January 2018, recommending, among other things, a ‘seamless system’ of health and social care and that individual and community involvement and personal control in care should be increased.¹⁵⁹ The Welsh Government’s 2017-2021 national strategy, ‘Prosperity for All’, cites social care as one of five key priorities.¹⁶⁰ Overall in Wales at the time of writing, there is a sense that social care is moving up the policy agenda.

6.2 Policy on independent living

In terms of developing policy on independent living or explicitly incorporating independent living into existing policy, the Welsh Government took action relatively late. At Westminster, the engagement of New Labour with disabled people’s organisations resulted in the direct introduction of independent living to policy documents in the mid-2000s.¹⁶¹ In 2005, the pivotal strategy document *Improving the Life Chances of Disabled People* placed independent living at the heart of the Westminster government’s disability policy.¹⁶² This was followed by the *Independent Living Strategy* in 2008.¹⁶³ A number of activists from the disabled people’s

<<https://seneddresearch.blog/2019/01/07/how-should-we-pay-for-social-care-in-the-future/>> accessed 18 July 2019.

¹⁵⁹ Welsh Government, ‘The Parliamentary Review of Health and Social Care in Wales: A Revolution from Within: Transforming Health and Social Care in Wales’ (2018)

<<http://gov.wales/docs/dhss/publications/180116reviewen.pdf>> accessed 6 March 2018.

¹⁶⁰ Welsh Government, ‘Prosperity for All: The National Strategy’ (2017)

<<http://gov.wales/newsroom/firstminister/2017/170919-new-national-strategy-for-a-more-prosperous-wales/?lang=en>> accessed 6 March 2018.

¹⁶¹ The first reference to a form of independence that reflected the notion of independent living found by the author in a major policy text occurred in Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Cm 5086, 2001), which states ‘Independence: Promoting independence is a key aim for the Government’s modernisation agenda. Nowhere is it of greater importance than for people with learning disabilities. While people’s individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. *Independence in this context does not mean doing everything unaided*’ (emphasis added), 23.

¹⁶² PMSU (n133). In ‘Life Chances’, independent living became one of four policy priorities in relation to disabled people. The others were employment, early years and family support and the transition to adulthood. ‘Life Chances’ was relevant only to England in respect of devolved matters. These formed the bulk of the document although certain matters, such as anti-discrimination legislation, were also discussed.

¹⁶³ Office for Disability Issues, ‘Independent Living: A Cross-Government Strategy about Independent Living for Disabled People’ (HM Government, 2008). The Independent Living Strategy pertained only to England.

movement were involved in the development of these documents,¹⁶⁴ which deployed the DRC definition of independent living.¹⁶⁵

The signing and the ratification of the UNCRPD in 2006 and 2009 respectively created a responsibility on UK governments to produce a domestic framework to implement the Convention.¹⁶⁶ Despite this, and the developments in Westminster, the Welsh Government was initially reluctant to develop a specific strategy in relation either to independent living or the UNCRPD. In its written response to the investigation of independent living by the Joint Committee on Human Rights, the Welsh Government stated '[i]ndependent living features in many of our policies and strategies across the Welsh Assembly Government' and argued that supporting independent living could be better achieved within the legislative framework provided by the Equality Act 2010 than by the introduction of a separate strategy.¹⁶⁷ However, by November 2011, the Welsh Government had altered its position, stating that the development of its Strategic Equality Plan (SEP) would be underpinned with a new strategy – a 'Framework for Action on Independent Living' – that would be developed in consultation with disabled people.¹⁶⁸ The decision was prompted by a combination of the Joint Committee investigation and the 2010-11 Disability Wales 'Independent Living NOW!' campaign.¹⁶⁹

¹⁶⁴ These included, among others: Jenny Morris, Jane Campbell, Bert Massie, Nasa Begum, Peter Beresford and John Evans.

¹⁶⁵ PMSU (n133). The DRC definition is provided in Chapter 2, section 4.

¹⁶⁶ This requirement is stated in Article 33 of the UNCRPD. The overall responsibility for implementing the UNCRPD remains with the UK government. Joint Committee on Human Rights, *Implementation of the Right of Disabled People to Independent Living* (2010-12, HL 257, HC 1074), 30-31.

¹⁶⁷ Welsh Assembly Government, 'Written Evidence Submitted by the Welsh Assembly Government (IL 61) (undated). Published in, Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (2011) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019, 313-338.

¹⁶⁸ Jane Hutt AM, 'Written Evidence submitted by Jane Hutt AM, Minister for Finance and Leader of the House, Welsh Government (IL 124) (November 2011). Published in, Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (2011) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019, 633-639.

¹⁶⁹ Disability Wales certainly attributed the revised decision of the Welsh Government to its independent living campaign. It advised the Joint Committee in additional written evidence that the Minister had announced the development of the Framework at its AGM in October 2011, stating that the development had been in response to the Disability Wales campaign. See: Disability Wales, 'Additional Written Evidence submitted by Disability Wales (IL 39A) (undated) Published in, Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (2011) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019, 170-171.

The Welsh Government's *Framework for Action on Independent Living* was published in September 2013.¹⁷⁰ It was the Government's first pan-disability strategy and set out the actions being taken by the Welsh Government to implement the UNCRPD including Article 19. This document is currently being revised. Owing to timing, it was not possible to include an analysis of the revised policy in this study, but there is discussion of it in Chapter 12.

7. Conclusion

One of the stated reasons for devolving policy and legislative power to Wales was the development of a government that was more open, accessible and accountable. This arguably provides strong opportunities for an activist counter-narrative devised by a grassroots movement to be taken up into state policy and legislation. It is therefore a particularly relevant context for the study of what happens to such a counter-narrative on this incorporation. If one of the reasons for the existence of the Welsh institutions of governance is to enable open and inclusive politics, it is worth finding out whether ideas that originate from or are embraced by Welsh people are accurately reproduced when they find their way into Welsh policy and law. The following chapter establishes independent living as a counter-narrative and sets out the key points of counter-narrative theory.

¹⁷⁰ Welsh Government, 'Framework for Action on Independent Living' (2013). The Framework is discussed in Chapter 10.

Chapter 4: Independent living and counter-narrative

1. Introduction

This thesis positions independent living as a counter-narrative of the disabled people's movement and examines the impact on it when it is incorporated into policy. Chapter 2 demonstrates that the distinctive feature of the disabled people's movement in the UK was its questioning not simply of the circumstances faced by disabled people, but the nature of disability itself and, by implication, the identity of disabled people. The movement was not simply interested in but *characterised by* the conscious and intentional act of narrative re-construction. This chapter sets out the theoretical landscape of counter-narrative development and use. It describes how counter-narratives are used in research, identifies where the theoretical discussion is lacking, and develops certain aspects to enable the study of the use of counter-narratives in policy and legislation. The chapter then considers counter-narrative development as an activity of the UK disabled people's movement and identifies both the social model of disability and independent living as counter-narratives. It concludes with a presentation of the theoretical tools that are used in the thesis.

2. The role of counter-narratives

It has already been stated that counter-narratives are those created and deployed by individuals or groups to question or challenge 'master narratives' or dominant social accounts. Within the literature, master narratives are essentially defined as the shared stories, ideas and understandings that circulate in society and create and uphold certain social norms. They are typically not examined or contested, but form

an essential element of how people view their world, acting – in Delgado’s words – ‘like eyeglasses we have worn a long time’.¹ But while they appear to be neutral, reflecting what appear to be ‘universal truths’,² they contain and reflect values that privilege certain groups and individuals and marginalise others.³ Master narratives may not be *intentionally* deployed by social actors, but they form the ‘normative points of reference’ against which individuals and groups are measured and judgements made.⁴ Master narratives ascribe deficit, inferiority or failure to certain people and groups, according to the terms and norms of the dominant group.⁵ Across the canon, master narratives are located within and extracted from a wide range of sources: fairy tales, works of great literature, ‘movie classics’⁶ and other media representations,⁷ policy,⁸ medical literature,⁹ institutional policies and practices,¹⁰ ‘foundational myths’¹¹ and ‘widely-accepted accounts of historical events’.¹² They are seen to constrain and to be reinforced by academic research¹³ and to exist within broad social behaviours such as ‘gendered role expectations’.¹⁴

Counter-narratives are described as those which contest the social norms that master narratives create and perpetuate. Certain authors suggest that a counter-

¹ Richard Delgado, ‘Storytelling for Oppositionists and Others: A Plea for Narrative’ (1989) 87 Michigan Law Review 2411, 2413.

² Shaun R Harper, ‘Niggers No More: A Critical Race Counternarrative on Black Male Student Achievement at Predominantly White Colleges and Universities’ (2009) 22(6) International Journal of Qualitative Studies in Education 697, 701.

³ Daniel G Solórzano and Tara J Yosso, ‘Critical Race Methodology: Counter-Storytelling as an Analytical Framework for Education Research’ (2002) 8(1) Qualitative Inquiry 23.

⁴ *Ibid.*, 28.

⁵ See, for example, Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Cornell University Press 2001); Harper (n2); Gabriel A Acevedo, James Ordner and Miriam Thompson, ‘Narrative Inversion as a Tactical Framing Device: The Ideological Origins of the Nation of Islam’ (2010) 20(1) Narrative Inquiry 124; Solórzano and Yosso describe various master narratives which contribute to a ‘cultural deficit model’. Solórzano and Yosso, ‘Critical Race Methodology’ (n2) 31.

⁶ Nelson (n5) 7.

⁷ Harper (n2) 698; Brett Smith and Andrew C Sparkes, ‘Men, Sport, Spinal Cord Injury, and Narratives of Hope’ (2005) 61 Social Science & Medicine 1095.

⁸ Shawn A Cassiman, ‘Of Witches, Welfare Queens, and the Disaster Named Poverty: The Search for a Counter-Narrative’ (2006) 10(4) Journal of Poverty 51.

⁹ Alexandra L Adame and Roger M Knudson, ‘Beyond the Counter-Narrative: Exploring Alternative Narratives of Recovery from the Psychiatric Survivor Movement’ (2007) 17(2) Narrative Inquiry 157.

¹⁰ Nelson (n5); Adame and Knudson (n9).

¹¹ Nelson (n5) 6-7.

¹² Acevedo, Ordner and Thompson (n5).

¹³ Solórzano and Yosso, ‘Critical Race Methodology’ (n3); Adame and Knudson (n9); Harper (n2).

¹⁴ E J Lawless, ‘Transforming the Master Narrative: How Women Shift the Religious Subject’ (2003) 24(1) Frontiers: A Journal of Women’s Studies 61, as cited in Acevedo, Ordner and Thompson (n5) 125.

narrative may simply be a way for an individual (or a group) to express their own experience when they find that their story does not 'fit' with that conveyed by dominant narratives.¹⁵ Others refer to conscious acts of defiance against narratives that, in privileging some, oppress others.¹⁶ Counter-narratives can be an intentional or unintentional means of demonstrating to the self or others that there are different possibilities for individuals and society,¹⁷ or used to build a group identity.¹⁸ Whatever their form, there is general agreement that, at some level, a counter-narrative incorporates the idea of *resistance* to master narratives which exclude, marginalise, subjugate or fail certain groups of people,¹⁹ or which characterise them as deficient.²⁰ Nelson describes them as 'narrative acts of insubordination'.²¹

Counter-narratives are therefore considered to perform the act of 'narrative repair' for identities that are damaged and distorted by assumptions and portrayals embedded in socially dominant discourses which enable or justify privilege, oppression, and restrictions on agency.²² Through the creation of a counter-narrative the individual or 'outgroup'²³ is said to assert their own experience and create their own reality,²⁴ exposing and correcting 'misrepresentations' and undermining the master narrative, requiring both the oppressor and the oppressed to adjust their perceptions.²⁵ In this way, the individual or group challenges dominant cultural assumptions²⁶ and engages in an act of re-definition through which their identity is reclaimed and their

¹⁵ Molly Andrews, 'Introduction: Counter-Narratives and the Power to Oppose' (2002) 12(1) Narrative Inquiry 1.

¹⁶ For example, Harper (n2); Delgado (n1).

¹⁷ Delgado (n1) (particularly at 2414); Solórzano and Yosso, 'Critical Race Methodology' (n3), 36.

¹⁸ Acevedo, Ordner and Thompson (n5); Adame and Knudson (n9); Delgado (n1).

¹⁹ Molly Andrews, 'Introduction' (n15); Nelson (n5); Solórzano and Yosso 'Critical Race Methodology' (n3); Delgado (n1); Lynn M Harter and others, 'Freedom through Flight: Performing a Counter-Narrative of Disability' (2006) 34(1) Journal of Applied Communication Research 3.

²⁰ Solórzano and Yosso 'Critical Race Methodology' (n3); Harper (n2); Anke Piekut, "'Brown Eyes are not the Same as Blue Eyes'" (2017) 27(2) Narrative Inquiry 378.

²¹ Nelson (n5) 8.

²² The term 'narrative repair' and the express focus on agency and opportunity are used in particular by Nelson, although others express the same ideas. Nelson (n5).

²³ This term is borrowed from Delgado. Delgado (n1) 2412.

²⁴ Delgado (n1).

²⁵ Ibid.

²⁶ Anita Harris, Sarah Carney and Michelle Fine, 'Counter Work: Introduction to "Under the Covers: Theorising the Politics of Counter Stories"' (2001) 4 Critical Psychology 6.

agency redeveloped and empowered.²⁷ In particular, it is argued that counter-narratives have a role in resisting *internalised* damage – the perceptions of the self created when individuals come to absorb, accept and believe the values attributed to them by master narratives.²⁸ Such damage is considered to be particularly insidious, causing an individual to form, view and evaluate their own identity according to the values and agenda of the dominant group and undermining agency from within.²⁹ Nelson describes the damage done to a person's identity and agency through oppressive narratives deployed by others as 'deprivation of opportunity' and the damage done by internalised narratives as 'the infiltrated self'.³⁰

2.1. The importance of the group and 'communities of choice' in counter-narrative development

The importance of groups in enabling both counter-narrative development and the re-creation of identity is a recurring theme in counter-narrative literature. Nelson examines the role of the group in some detail. Following Friedman,³¹ Nelson distinguishes between 'found communities' – the social groups to which we belong by default (such as families, neighbourhoods, schools) and 'communities of choice' – the groups we seek out or form voluntarily.³² While both are essential to identity constitution, Friedman (and Nelson) argue that their roles are distinct, suggesting

²⁷ Nelson (n5); Farah Godrej, 'Spaces for Counter-Narratives: The Phenomenology of Reclamation' (2011) 32(3) *Frontiers: A Journal of Women Studies* 111; Smith and Sparkes (n7); Adame and Knudson (n9).

²⁸ This theme is widely expressed but explored in particular by Nelson (n5) and Godrej (n27). See also: Andrews 'Introduction' (n15); Solórzano and Yosso, 'Critical Race Methodology' (n3). For an example of internalised damage found in interview data, see Clare Connors and Kirsten Stalker, 'Children's Experiences of Disability: Pointer to a Social Model of Childhood Disability' (2007) 22(1) *Disability & Society* 19. The notion of internalised damage echoes Marx's idea of a 'false consciousness, in which members of oppressed classes assumed the ideas imposed upon them' and Gramsci's theory of hegemony, which argues that members of underclasses 'unwittingly identify with the values promoted by the bourgeoisie and accept the *status quo* rather than rebelling'. John Flowerdew and John E Richardson, 'Introduction' in John Flowerdew and John E Richardson (eds), *The Routledge Handbook of Critical Discourse Studies* (Routledge 2018), 4.

²⁹ Nelson (n5) particularly 28-34; Godrej (n27).

³⁰ Nelson (n5) particularly 23-34.

³¹ Marilyn Friedman, 'Feminism and Moral Friendship: Dislocating the Community' in Eve Browning Cole and Susan Coultrap-McQuin (eds), *Explorations in Feminist Ethics: Theory and Practice* (University of Indiana Press 1992).

³² Nelson (n5) 9-11 and ch 5.

that found communities contribute to the creation of an ‘unreflective, “given” identity’, while communities of choice enable identity ‘reconstitution’ or ‘renegotiation’.³³ In communities of choice, members are able to consider the social values they are expected to observe, share doubts and new information and offer different interpretations, assisting members and the community as a whole to devise revised moral codes and new ways of being.

Nelson argues not only that these communities create the space for counter-narratives to be developed, but that they have a key role in transforming them from the ineffective to the effective. She suggests that a story of resistance is useless unless it is accepted by others, and that the distinctive social standards existing in a community of choice are able to legitimate a particular narrative, enabling it to gain traction and begin the move from the personal to the wider context.³⁴ Godrej expands on Nelson’s work, maintaining that communities of choice perform various ‘autonomy-competency skills’ required for the development of new narratives of identity.³⁵ Nelson and Godrej suggest that is through the work of a ‘community of choice’ that a narrative of resistance moves from the individual, personal level (at which it may be conscious or unconscious), to an *activist* discourse which has the capacity to bring about social change.³⁶ Whether a community of choice is necessary for this process is questionable – it is certainly arguable that groups may also form counter-narratives within found communities and, indeed, that these groups are not entirely or necessarily distinct. The need for a *group* activity, however, is essential for the development of a counter-narrative that consciously seeks structural change. While an individual acting alone can question and resist master narratives, group activity is necessary to enable the spread and ‘hold’ of ideas, and to develop consensus around and legitimate the counter-narratives and the desired form of the reconstructed identity. In the disability context, for example, Adame and Knudson, note that it was the coming together of groups of people who identify as psychiatric

³³ Friedman (n31) 92, cited by Nelson (n5) 9.

³⁴ Nelson (n5) 87.

³⁵ Godrej (n27).

³⁶ Some studies suggest how this might happen in practice. For example, Shelly Grabe and Anjali Dutt, ‘Counter Narratives, the Psychology of Liberation and the Evolution of a Women’s Social Movement in Nicaragua’ (2015) 21(1) *Peace and Conflict: Journal of Peace Psychology* 89.

survivors that enabled the transformation of personal experiences into new narratives and social action.³⁷

While such groups develop and legitimate counter-narratives, they also act to quell internal dissent. In the US disability context, Barton describes the struggle between dominant and counter-narratives within groups of parents navigating the world of 'special education'.³⁸ Arguing that the characterisation of disabled people as rights-bearers is a broad counter-narrative of US disability rights movements, Barton discusses how, within these groups, this functions as the essential *master* narrative, to which new counter-narratives – of parental frustration, fear and failure – emerged, only to be shut down.

3. The use of counter-narratives in research and theoretical approaches to counter-narratives

Although the use of counter-narrative as an analytical tool has developed over the last three decades, the origin of the idea is typically unattributed. While those using the term trace the idea of *master* narrative back to various thinkers, including Lyotard,³⁹ Lévi-Strauss,⁴⁰ and Gramsci,⁴¹ no individual is credited with identifying the concept of counter-narrative. However, the notion of counter-narratives arose and was articulated largely through the study of matters of race, and is a core element of critical race theory (CRT), which posits 'the centrality of experiential knowledge' and

³⁷ Adame and Knudson (n9).

³⁸ Ellen Barton, 'Disability Narratives of the Law: Narratives and Counter-Narratives' (2007) 15(1) Narrative 95.

³⁹ Lyotard is typically identified as the first individual to use the terms 'grand récit' and 'metanarrative'. Jean-François Lyotard, *The Postmodern Condition: A Report on Knowledge* (Geoff Bennington and Brian Massumi trs, Manchester University Press 1984). For citations, see: Michael Bamberg, 'Master Narrative' in David Herman, Manfred Jahn and Marie-Laure Ryan (eds), *Routledge Encyclopedia of Narrative Theory* (Routledge 2005); Acevedo, Ordner and Thompson (n5); Immy Holloway and Dawn Freshwater, 'Vulnerable Story Telling: Narrative Research in Nursing' (2007) 12(6) Journal of Research in Nursing 703; Cate Watson, "'Teachers are Meant to be Orthodox": Narrative and Counter-Narrative in the Discursive Construction of "Identity" in Teaching' (2009) 22(4) International Journal of Qualitative Studies in Education 469.

⁴⁰ Delgado (n1) citing Claude Lévi-Strauss, 'The Structural Study of Myth' (1955) 66 Journal of American Folklore 428.

⁴¹ Ibid, citing Antonio Gramsci, *Selections from the Prison Notebooks* (Quintin Hoare and Geoffrey Nowell Smith eds and trs, Lawrence and Wishart 1971).

'the challenge to the dominant ideology' as central tenets of understanding the minority ethnic experience.⁴² While the examination of counter-narratives has also featured particularly in feminist studies,⁴³ and has extended to the study of a wide range of experiences, including those of nurses,⁴⁴ teachers,⁴⁵ people undergoing medical procedures,⁴⁶ those who have grown up in challenging circumstances,⁴⁷ older people,⁴⁸ mothers,⁴⁹ and disabled people (and their families),⁵⁰ there is little consideration within this literature of the origins of the idea of counter-narratives. Rather, the literature implies that counter-narratives simply exist, almost as 'fact' or as a logical inference of the existence of dominant social accounts. Andrews refers to 'the phenomenon of counter-narratives', suggesting that counter-narratives are some form of naturally arising social artefacts.⁵¹

3.1. Different groups of researchers

Within the academic literature using counter-narrative theory, there are three main groups of thinkers who, in general, do not borrow from or refer to each other, but whose work is roughly contemporaneous. Those working in the field of CRT typically use a distinct form of counter-narrative in which the researcher creates particular

⁴² H Richard Milner IV and Tyrone C Howard, 'Counter-Narrative as Method: Race, Policy and Research for Teacher Education' (2013) 16(4) *Race, Ethnicity and Education* 536; Solórzano and Yosso, 'Critical Race Methodology'.

⁴³ For example: Mary Romero and Abigail J Stewart (eds), *Women's Untold Stories: Breaking Silence, Talking Back, Voicing Complexity* (Routledge 1999); Nelson (n5); Hilde Lindemann Nelson, 'Sophie Doesn't: Families and Counterstories of Self-Trust' (1996) 11(1) *Hypatia*, 91; Godrej (n27); C Cohn, 'Sex and Death in the Rational World of Defense Intellectuals' (1987) 12 *Signs* 687, cited in Jean Talbot et al, 'Affirmation and Resistance of Dominant Discourses: The Rhetorical Construction of Pregnancy' 1996 6(3) *Journal of Narrative and Life History* 225.

⁴⁴ Holloway and Freshwater (n39).

⁴⁵ Watson (n39).

⁴⁶ Karen Throsby, 'Negotiating "Normality" when IVF Fails' (2002) 12(1) *Narrative Inquiry* 43.

⁴⁷ Molly Andrews, 'Memories of Mother: Counter-Narratives of Early Maternal Influence' (2002) 12(1) *Narrative Inquiry* 7.

⁴⁸ Rebecca L Jones, "'That's Very Rude, I Shouldn't Be Telling You That": Older Women Talking about Sex' (2002) 12(1) *Narrative Inquiry* 121.

⁴⁹ Talbot et al (n43); Sarah Carney, 'Analysing Master Narratives and Counter Stories in Legal Settings: Cases of Maternal Failure-to-Protect' (2001) 4 *International Journal of Critical Psychology* 61.

⁵⁰ Smith and Sparkes (n7); Pamela Fisher and Dan Goodley, 'The Linear Medical Model of Disability: Mothers of Disabled Babies Resist with Counter-Narratives' (2007) (1) *Sociology of Health & Illness* 66; Adame and Knudson (n9).

⁵¹ Molly Andrews, 'Introduction' (n15) 1. For reference, the earliest article found by the author using the term 'counterstory' to refer to the concept outlined above is dated 1989 in Delgado (n1).

hypothetical situations and characters, and devises dialogues for these characters, to illustrate the social experiences of marginalised groups. In these cases, the counter-story is a methodological tool within an explicitly activist research agenda. CRT argues that academic research itself is bound by and perpetuates dominant narratives that exclude minority experiences,⁵² but is presented as neutral, objective and complete.⁵³ Bell, Delgado, Stefancic, Solórzano and Yosso are key contributors to this work.⁵⁴ This thesis does not engage with this form of counter-narrative, although it draws from the theoretical work of these researchers, particularly in relation to the role and impact of master narratives. Adjacent to this is a discussion between various researchers who identify counter-narratives which are consciously or unconsciously created by their research participants as a means of navigating their own lives. The aim of this work is to consider master and counter-narratives to examine how the individuals themselves make sense of their 'outgroup' or non-conforming activities, or negotiate and attempt to reformulate dominant social codes that do not encompass their experiences. Much of the theoretical discussion is centred around a special issue of the journal 'Narrative Inquiry' (elsewhere called the 'considering counter-narratives' or 'CCN' debate⁵⁵) although work using counter-narrative theory extends well beyond this.⁵⁶ This work centres in particular around how individuals talk about and live their own, everyday lives, and may or may not consider conscious resistance. Many authors use counter-narrative theory in this way, although the theoretical work of Bamberg is particularly influential.⁵⁷

⁵² A full description of this process and discussion of the rationale behind it is contained in: Solórzano and Yosso, 'Critical Race Methodology' (n3). For a further example of this process, see Harper (n2).

⁵³ Harper (n2), 701-702; Solórzano and Yosso, 'Critical Race Methodology' (n3) 32.

⁵⁴ Derrick A Bell, 'Who's Afraid of Critical Race Theory?' (1995) 4 *University of Illinois Law Review* 893; Delgado (n1); Richard Delgado and Jean Stefancic, *Critical Race Theory: An Introduction* (New York Press 2001); Richard Delgado and Jean Stefancic (eds) *Critical Race Theory: The Cutting Edge* (2nd edn, Temple University Press 2000); Solórzano and Yosso, 'Critical Race Methodology' (n3); Daniel G Solórzano and Tara J Yosso, 'A Critical Race Counterstory of Race, Racism and Affirmative Action' (2002) 35(2) *Equity and Excellence in Education* 155. For citations of the work of Solórzano and Yosso see, among others: Milner and Howard (n42) and Harper (n2).

⁵⁵ This is the name given by Acevedo, Ordner and Thompson (n5). The relevant issue is *Narrative Inquiry* 2002, issue 12(1) (with some further consideration in issue 12(2)).

⁵⁶ See, for example, in addition to various articles, the special edition of *Critical Psychology* (2001) published as Michelle Fine and Anita Harris (eds), *Under the Covers: Theorising the Politics of Counter Stories* (Lawrence and Wishart 2001); and Mary Romero and Abigail J. Stewart (eds), *Women's Untold Stories: Breaking Silence, Talking Back, Voicing Complexity* (Routledge 1999).

⁵⁷ In particular, Michael Bamberg, 'Considering Counter Narratives' in Michael Bamberg and Molly Andrews (eds), *Considering Counter-Narratives: Narrating, Resisting, Making Sense* (John Benjamins Publishing 2004).

Finally, there is the work of Nelson, who writes from a background of philosophy and ethical analysis. Nelson focuses on a more abstract exploration of the role of master and counter-narratives, considering the connection of identity to agency, and how counter-narratives go about the work of reparation and reclamation, illustrating her points with discussion of the narrative construction of gypsies, transsexuals, mothers and nurses.⁵⁸ While Nelson focuses on stories of everyday life, she considers in particular how these can be extended to more organised resistance, and argues that a story of identity repair can only be considered a counter-narrative if it fulfils certain criteria. These are: that the story is 'identity-constituting', that it has a relationship of resistance with master narratives, and that those master narratives are generated by oppressive forces which impose an identity on subgroups that 'marks its members as morally defective'. In addition, Nelson argues that counter-narratives must be intentional acts of 'moral self-definition' that intend to repair this identity damage and liberate agency and that they can become (non-oppressive) master narratives in their own right.⁵⁹

Despite the differences of approach to the use and configuration of counter-narratives, these three groups of researchers share certain elements, which might be defined as 'core ideas' of counter-narrative theory. There is broad consensus on the existence, purpose and impact of master narratives as told and re-told social stories that present as, or purport to be, neutral social 'facts'; and the positioning of counter-narratives as a form of challenge to, or a disruption of, these. The focus on the reconstruction of identity and – more implicitly – agency is a uniting theme, as is the notion of resistance to marginalisation, oppression, unequal power relations and narratives of deficit as a characterising feature of the outgroup.⁶⁰

⁵⁸ Nelson (n5).

⁵⁹ Ibid, ch 5 and particularly 156-157.

⁶⁰ See section 2 and note 5 above. Solórzano and Yosso in particular refer to a 'cultural deficit model' to explain educational inequity. Solórzano and Yosso, 'Critical Race Methodology' (n3) 30-32.

3.2. 'Everyday' and 'activist' counter-narratives

There is little exploration in the literature of the distinction between counter-narratives which form part of individuals' everyday lived experiences, and those which are deployed in a more organised fashion to bring about some form of social or political change, although the difference is noted.⁶¹ In this thesis these are distinguished and termed 'everyday' and 'activist' counter-narratives respectively.⁶² This section sets out the distinctions between these two counter-narrative forms.

Everyday counter-narratives operate on a personal level. Across the literature there are many and various examples of individual narratives, expressed through words or actions, which are an attempt to make sense of an experience that is unspoken or marginalised within dominant social expectations, or a form of conscious or unconscious resistance to some cultural norm. While they challenge, they may or may not seek change. Carney, for example, identifies the activities and experiences described by a teenage mother as a counter-narrative to dominant stories of responsible mothering;⁶³ and Kitzinger considers how women with breast cancer resisted social expectations to 'think positive'.⁶⁴ The majority of authors using counter-narrative theory, (including those within the 'CCN debate') are concerned with 'everyday' counter-narratives. In this context, Kölbl makes an important distinction between those who simply tell their stories, which happen to be counter to others; and those who intentionally position themselves in relation to constraining narratives.⁶⁵

'Activist' counter-narratives extend resistance beyond the everyday and individual life and form an attempt to construct or reconstruct identity and agency on a wider scale

⁶¹ See, for example, Andrews, 'Introduction' (n15).

⁶² Coincidentally, similar terminology is used to describe different forms of agency among disabled people in a recent study that examines the output of two campaigns by disabled activists in the UK. Trevisan uses the terms 'everyday' and 'political' agency to describe their contribution to their own daily lives and their contribution to a 'collective political body'. Filippo Trevisan, 'Crowd-Sourced Advocacy: Promoting Disability Rights through Online Storytelling' (2017) 6(2) *Public Relations Inquiry* 191, 200.

⁶³ Sarah Carney (n49).

⁶⁴ Celia Kitzinger, 'Resistance in Women's Talk: Thinking Positively about Breast Cancer?' (2001) 4 *Critical Psychology* 35.

⁶⁵ Carlos Kölbl, 'Blame it on Psychology!?' (2002) 12(1) *Narrative Inquiry* 29.

than the personal. They actively seek to implement some form of change and are therefore always conscious forms of resistance. Activist counter-narratives are constructed by groups of individuals working together, and work on *both* the individual *and* the collective level. They may be the messages promoted within a particular 'contained' environment or extend to a broader social context. Thus, for example, Nelson discusses the activities of a (hypothetical) group of nurses seeking to demonstrate their individual and group competence within their workplace,⁶⁶ Acevedo et al examine the separatist message emerging from the Nation of Islam as a counter-narrative that attacks both master narratives of race and the more moderate opposition of the 'mainstream' civil rights movement,⁶⁷ and Grabe and Dutt explore how women in Nicaragua drew on their own experiences to create a political counter-narrative of inclusion and rights which underpinned the development of a women's social movement.⁶⁸

These two categories are not entirely distinct. Adame and Knudson demonstrate how the politicised identity of the psychiatric survivor movement emerged from the lived experiences of individuals;⁶⁹ and a mural painted by young women in Brooklyn discussed by Bertram hovers between the personal and the political.⁷⁰ However, ultimately these forms of counter-narrative have different audiences and serve different purposes. Other than in the work of Nelson – who considers how narratives can move from the personal to the organised context – there is little exploration of the role of the latter in the literature although some discussion exists.⁷¹

In this thesis, independent living is positioned as an activist counter-narrative. Consideration is given to how this was built out of individual acts of personal resistance more attuned to everyday counter-narratives and developed into a series of activist principles. There is examination of how independent living operates at an

⁶⁶ Nelson (n5).

⁶⁷ Acevedo, Ordner and Thompson (n5).

⁶⁸ Grabe and Dutt (n36).

⁶⁹ Adame and Knudson (n9).

⁷⁰ Corrine Bertram, 'Enduring impermanence: A Neighbourhood Contra (Counter)-versy (Against Verse)' (2001) 4 *International Journal of Critical Psychology* 123.

⁷¹ For example: Acevedo, Ordner and Thompson (n5); Adame and Knudson (n9); Alicia A Broderick and Ari Ne'eman, 'Autism as Metaphor: Narrative and Counter-Narrative' (2008) 12 *International Journal of Inclusive Education* 459.

individual and group level – that is, how independent living may be used by an individual to repair their own damaged identity, and how it has been used by the disabled people’s movement to repair the ‘disabled identity’ more widely.

4. Counter-narrative and policy

The aim of this thesis is to consider both the role of independent living as an activist counter-narrative that repairs the identity and agency of disabled people, and what happens to that counter-narrative when it is exported from its social movement roots into policy. It is necessary therefore to consider the relationship between master and counter-narratives and policy. This section examines how the existing literature delineates this relationship.

Within counter-narrative literature, policy – in terms of government strategy, actions or documentation – is relatively rarely explicitly identified as a creator or repository of either master or counter-narrative. Similarly, interpretive and narrative analyses of policy tend not to engage with the notion of activist counter-narratives as they are outlined in this chapter. In the field of policy analysis the terms ‘counter-narrative’ and ‘counterstory’ typically carry different meanings. In some cases they describe a narrative that occurs in discussion around policy which is simply different from the dominant account.⁷² They may also apply to alternative policy ideas devised and considered by researchers as a means of reconceptualising a policy issue or shifting policy direction.⁷³ Such ideas may overlap with the form of counter-narratives discussed in this thesis as the ideas discussed by academics may be based on the counter-narratives devised by individuals or groups. The term ‘counterstory’ also occurs within Roe’s model of metanarrative policy analysis, devised to examine

⁷² For example, John Boswell, ‘The Performance of Political Narratives: How Australia and Britain’s “Fat Bombs” Fizzled Out’ (2016) 18(3) *The British Journal of Politics and International Relations* 724.

⁷³ See, for example: Cassiman (n8); Alistair Hewison and Kevin Morrell, ‘Leadership Development in the English National Health Service: A Counter Narrative to Inform Policy’ (2014) 51 *International Journal of Nursing Studies* 677; Jennifer Gore and others, ‘Who Says we are not Attracting the Best and Brightest: Teacher Selection and the Aspirations of Australian School Students’ (2016) 43 *Aust. Educ. Res.* 527.

ambiguity and controversy in particular policy fields.⁷⁴ In this latter situation, the notion of ‘counterstory’ performs a specific methodological role which is not relevant to this thesis. There are, however, some studies of the intersection of activist counter-narratives and policy,⁷⁵ and others that extend this discussion to the relationship between activist counter-narratives and law.⁷⁶

Unsurprisingly, given the authority of policy, and its role in the construction of identity, social roles and the relationship between the individual and the state,⁷⁷ where policy is considered within counter-narrative literature, it is typically considered to be a location or source of master narratives.⁷⁸ Policy does not simply exist in the actions, decisions and high level documents of government – it is equally created by the actors who interpret these documents and decisions and implement them both at managerial and frontline level,⁷⁹ at which point the original intentions of policy makers may be lost or subverted.⁸⁰ These institutional policies and practices are also on occasion identified as the creators or repositories of master narratives.⁸¹

Within the counter-narrative literature, policy, therefore, appears to have a close connection with the creation, the reproduction and the reinforcement of master narratives. Similar ideas are found in other bodies of literature which do not explicitly use the concept of counter-narratives. Feminist scholars in the US have argued that

⁷⁴ Roe sets out his model in: Emery Roe, *Narrative Policy Analysis: Theory and Practice* (Duke University Press 1994). The key stages of his model are set out by Fischer in Frank Fischer, *Reframing Public Policy: Discursive Politics and Deliberative Practices* (OUP 2003).

⁷⁵ For example, Jukka Nyysönen, ‘Sami Counter-Narratives of Colonial Finland. Articulation, Reception and the Boundaries of the Politically Possible’ (2013) 30(1) *Acta Borealia* 101.

⁷⁶ Delgado and Stefancic comment in particular on legal narrative and storytelling. Delgado (n1); Delgado and Stefancic *Critical Race Theory; An Introduction* (n54). Another study of the intersection of an activist counter-narrative and law is Grabe and Dutt (n36).

⁷⁷ Cris Shore and Susan Wright, ‘Policy: A New Field in Anthropology’ in Cris Shore and Susan Wright (eds) *Anthropology of Policy: Critical Perspectives on Governance and Power* (Routledge 1997).

⁷⁸ See, for example: Cassiman (n8); Frode F Jacobsen, ‘Understanding Public Elderly Care Policy in Norway: A Narrative Analysis of Governmental White Papers’ (2015) 34 *Journal of Aging Studies* 199. Barton (n38, 95) refers to ‘political narratives of disability’ and the role of law in upholding these.

⁷⁹ Stephen J Ball, ‘What is Policy? Texts, Trajectories and Toolboxes’ (1993) 13(2) *Discourse: Studies in the Cultural Politics of Education* 10.

⁸⁰ Michael Lipsky, *Street-Level Bureaucracy: Dilemmas of the Individual in Public Services* (Russell Sage Foundation 1980).

⁸¹ See, for example, the assumptions within the hospital and attitudes of the medical staff described by Nelson (n5) 1-6; the medical literature and practices outlined by Adame and Knudson (n9); the multiple social failures leading to the exclusion of disabled people described by Harter et al (n19); the ‘overarching’ dominant narrative constructed by colleges of further education identified by Piekut (n20); and the ‘niggering’ attitudes identified by Harper (n2) in US college education.

successive US administrations have drawn on existing socially available tropes to construct groups of individuals as 'welfare dependents' with the result that certain social inequalities are normalised⁸² - an example of policy directly deploying and reproducing master narratives for a particular social end. Scholars taking an anthropological approach to policy analysis stress its role in creating controlling discourses and hegemonic power;⁸³ and interpretive policy analysis, drawing on discourse theory, holds that underlying assumptions and 'taken for granted' perceptions of the social world dictate what can be discussed, in terms of the construction not just of policy solutions, but of the matters that are considered at all.⁸⁴

There is, therefore, a general consensus that policy is both constrained by dominant discourses and reproduces and re-forms certain ideas and narratives. In the UK, disabled activists have certainly argued that policy has a particular role in the construction and problematizing of disability,⁸⁵ and that dominant narratives relating to disability have underpinned particular policy and legislative initiatives.⁸⁶ Policy is therefore typically connected, intentionally or unintentionally, with the production and reinforcement of master narratives. This is not to say that policy contains or promotes *consistent* narratives. While the existence of master narratives suggests some form of coherent world view, policy products – even when ideologically driven – are frequently required to obscure difference. The policy project is a process of pulling together diverse – even opposing – views and priorities into something that

⁸² Nancy Fraser and Linda Gordon, "'Dependency' Demystified: Inscriptions of Power in a Keyword of the Welfare State' (1994) *Social Politics* 4; Martha Fineman, *The Autonomy Myth: A Theory of Dependency* (New Press 2004).

⁸³ Shore and Wright (n77); Raymond Apthorpe, 'Writing Development Policy and Policy Analysis Plain or Clear: On Language, Genre and Power' in Cris Shore and Susan Wright (eds) *Anthropology of Policy: Critical Perspectives on Governance and Power* (Routledge 1997).

⁸⁴ Ball (n79); Karen Monkman and Lisa Hoffman, 'Girls' Education: The Power of Policy Discourse' (2013) 11(1) *Theory and Research in Education* 63, citing J Gee, *Social Linguistics and Literacies: Ideology in Discourses* (3rd edn, Routledge 2008) and G Lakoff, *Don't Think of an Elephant! Know Your Values and Frame the Debate* (Chelsea Green Publishing 2004).

⁸⁵ Victor Finkelstein, 'Attitudes and Disabled People: Ideas for Discussion' (World Rehabilitation Fund 1980, reprinted by RADAR) <<http://pf7d7vi404s1dxh27mla5569.wpengiengine.netdna-cdn.com/files/library/finkelstein-attitudes.pdf>> accessed 5 February 2018.

⁸⁶ Oliver, for example, argues that policy has not 'shaken off the shackles of "personal tragedy theory"' and that one of the pivotal pieces of early social care legislation, the Chronically Sick and Disabled Persons Act 1970, reinforces master narratives of helplessness and dependence on professional expertise. Michael Oliver, 'Social Policy and Disability: Some Theoretical Issues' (1986) 1(1) *Disability, Handicap & Society* 5.

has the appearance of coherence and smoothing over instability and contestation.⁸⁷ In this context, Fischer argues that narratives are a means of creating a sense of coherence where conflict exists.⁸⁸

Similarly, the frequent connection between policy and master narratives does not mean that policy is *invariably* or *necessarily* a creator or upholder of master narratives. Nor does it mean that policy cannot refer to, contain, absorb or even be a counter-narrative. Certain policies – and their broader underpinning principles – may be created with the specific intention of contesting either ideas which have gone before or externally imposed policy contexts. Thus – to take very broad examples – the Thatcher Conservative administrations implemented public sector reforms which replaced collective principles that had previously been broadly tolerated across the political spectrum with those based on the principles of the market place;⁸⁹ and the Welsh Government has sought, and continues to seek, to differentiate itself from those Westminster policies of marketisation and austerity, and replace narratives of individualism with those of communitarianism.⁹⁰ Certain policies, therefore, are intentionally set out as opposition – and may themselves operate as broad counter-narratives – to the prevailing discourse. Depending on various circumstances, such narratives may, in time, themselves become master narratives in their own right, understood or accepted as a form of policy ‘common sense’.

The Welsh Government communitarian narrative, introduced in the preceding chapter, is certainly capable of being considered a counter-narrative. While a core purpose was to embed principles that were particularly prevalent in Wales, part of its purpose was certainly to establish a distinct Welsh political identity. The National Assembly for Wales and the Welsh Government are relatively new entities, seeking to make their mark both politically and in the public consciousness in Wales. An element of narrative repair was also in play – Wales has historically been subject to a certain level of dominance from England and Westminster which has included the

⁸⁷ Janet Newman and John Clarke, ‘Narrating Subversion, Assembling Citizenship’ in Marian Barnes and David Prior (eds) *Subversive Citizens: Power, Agency and Resistance in Public Services* (Policy Press 2009). For a discussion of the role of ‘assemblages’ in policy, see Catherine Needham, *Personalising Public Services: Understanding the Personalisation Narrative* (Policy Press 2011).

⁸⁸ Fischer (n74).

⁸⁹ Robert Page, *Revisiting the Welfare State* (OUP 2007).

⁹⁰ Chapter 3.

subjugation of the Welsh language and culture.⁹¹ This thesis does not set out to scrutinise the Welsh political narrative *itself* in terms of counter-narrative theory, but to consider the relationships between this narrative and independent living, and consider how these have impacted on the absorption of the independent living counter-narrative in Welsh Government policy and legislation.

The deliberate reference to or insertion of a specific counter-narrative in policy may also be one way in which conflict in policy is obscured, or subversive ideas neutralised. In relation to disability, in both Westminster and Wales, the insertion into policy of messages emerging from the disabled people's movement has been enabled by drives to involve disabled people more directly in policy development,⁹² and in both countries disabled activists have taken the opportunity to place both the social model and independent living (among other ideas) into the policy context.⁹³ In Westminster, the Blair and Brown years saw independent living welcomed into policy as a disruptive force, enabling a break with former ideas characterised as outdated.⁹⁴ In this context, independent living was set out as a justification for the new policy models of 'personalisation'.⁹⁵ Personalisation, however, is well recognised as a policy narrative that speaks to multiple ideologies and facilitates public sector marketisation, and certain disabled activists have suggested that it has acted as a form of 'colonisation' of the independent living narrative.⁹⁶ Similarly, Beckett and

⁹¹ Adam Price, *Wales: The First and Final Colony: Speeches and Writing 2001-2018* (y Lolfa 2018).

⁹² At Westminster, particularly in the Blair years, consultation with disabled people extended to the proactive inclusion of disabled people and DPOs in policy formation, including the drafting of policy texts, particularly 'Improving the Life Chances of Disabled People' and the Independent Living Strategy. See: Prime Minister's Strategy Unit and others, *Improving the Life Chances of Disabled People: Final Report* (TSO, 2005) and Office for Disability Issues and others, *Independent Living: A Cross-Government Strategy about Independent Living for Disabled People* (ODI, 2008). As discussed in Chapter 3, in the Welsh context one of the stated purposes of devolution was greater citizen engagement and the participation of civil society in political processes; and certain structures were established to facilitate this.

⁹³ In England, independent living was placed at the centre of disability policy in *Improving the Life Chances of Disabled People*. Prime Minister's Strategy Unit and others, *Improving the Life Chances of Disabled People: Final Report* (TSO, 2005). An Independent Living Strategy was developed in 2008. Office for Disability Issues and others, *Independent Living: A Cross-Government Strategy about Independent Living for Disabled People* (HM Government, 2008). In Wales, a 'Framework for Action on Independent Living' was introduced in 2013 which was under review at the time of writing. Welsh Government, *Framework for Action on Independent Living* (2013).

⁹⁴ PMSU (n92); ODI (n92).

⁹⁵ PMSU (n92). Personalisation is explained in Chapter 3, section 6.1.

⁹⁶ See, in particular, Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011). There is further consideration of this point in Chapter 6, section 4.4.

Campbell suggest that in being incorporated into policy, the social model has been 'co-opted by the state' to service a neoliberal agenda.⁹⁷

This suggests that there is a need to examine in detail what happens to counter-narratives when they are transposed into the policy or legal context. Marginalised groups may achieve particular impact if they can insert an activist counter-narrative into policy and law. National policy has a powerful influence on narratives that exist within society and on the material opportunities and identities available to different social groups, and the effective insertion of an activist counter-narrative into national policy has the potential for significant structural and cultural change for the benefit of the relevant group.⁹⁸ Outside the matter of counter-narrative theory, Löve and others cite Young in arguing that:

.... to change their position of oppression, marginalized groups must be a part of the political structure, engage in setting the agenda and defining the issues, and redefining the concepts that relate to their lives.⁹⁹

In relation to disability, this is now legally recognised. Article 4(3) of the UNCRPD requires states parties to consult disabled people's organisations in the development of policy which affects them.¹⁰⁰

Where an activist counter-narrative is concerned, such engagement may enable an outgroup to convert a subversive counter-narrative into a dominant policy narrative, dislodging the existing social assumptions and redrawing the master narratives at a critical level. However, the concerns of disabled activists in the UK outlined in

⁹⁷ Angharad Beckett and Tom Campbell, 'The Social Model of Disability as an Oppositional Device' (2015) 30(2) *Disability & Society* 270, 277.

⁹⁸ Grabe and Dutt (n36), for example, suggest that the passing of legislation can bring a counter-narrative into broader public discourse and create duties on certain bodies to promote change in certain 'sociocultural patterns'.

⁹⁹ Laufey Löve and others, 'The Inclusion of the Lived Experience of Disability in Policymaking' (2017) 6(33) *Laws* 1, 3, citing Iris M Young, *Justice and the Politics of Difference* (Princeton University Press, 1990). This work by Young is also cited extensively in Nelson's work on counter-narratives.

¹⁰⁰ It is well-recognised that participation in the policy process is vital if policy and law that disadvantage disabled people are to be successfully challenged. See, Löve and others, citing Mary Keys, 'Article 12 of the UN Convention on the Rights of Persons with Disabilities and the European Convention on Human Rights' in Charles O'Mahoney and Gerard Quinn (eds), *Disability Law and Policy: An Analysis of the UN Convention* (Clarus Press 2017).

Chapters 1 and 2 of this thesis demonstrate that this also entails risks. The incorporation of counter-narrative into policy may result in its co-optation or neutralisation, or simply the creation of a poorly understood or replicated model. The question arises as to whether the ideas found in an activist counter-narrative can remain intact in policy or law in terms of their purpose and content; and whether they achieve the intended narrative repair and retain their subversive potential. During this project, no studies were found that examined the impact on an activist counter-narrative itself of its importation into state discourse. This absence is addressed in this thesis. By comparing the constructions of independent living in the activist and policy texts, this thesis examines what happens to the counter-narrative of independent living in the Welsh policy and legal context.

5. Counter-narrative and disability studies

Delgado argues that there is an instinctive need of those in outgroups to tell their own stories.¹⁰¹ Disabled people are no exception. In 1966 Paul Hunt brought together a selection of self-stories in a collection entitled *Stigma*,¹⁰² and numerous autobiographies by disabled people are readily available.¹⁰³ In 1997, Couser noted the upsurge in ‘illness narratives’ over recent decades as increasing numbers of people have sought to express their own experience of illness or impairment, often as a means of coming to terms with the loss of control over one’s body that is, in modern western society, an inevitable part of the process of submitting to medical intervention.¹⁰⁴ Hacking suggests that the rise in ‘autiebiographies’ written by autistic

¹⁰¹ Delgado (n1) 2436.

¹⁰² Paul Hunt (ed), *Stigma* (Geoffrey Chapman 1966).

¹⁰³ See, for example, Caitlin Wood (ed), *Criptiques* (May Day Publishing 2014); John Elder Robison, *Look Me in the Eye: My Life with Autism* (Ebury Press 2008); Nancy Mairs, *Waist High in the World: A Life among the Non-Disabled* (Beacon Press 1996); Sheila Hocken, *Emma and I* (Victor Gollancz 1977); Hector Chevigny, *My Eyes Have a Cold Nose* (Yale University Press 1946); Helen Keller, *The Story of My Life* (Doubleday, Page & Company 1903).

¹⁰⁴ G Thomas Couser, *Recovering Bodies: Illness, Disability and Life Writing* (University of Wisconsin Press 1997).

people¹⁰⁵ is generating new ways of talking about, and living, autistic lives;¹⁰⁶ and social media is now widely used by disabled people to describe and comment on experiences and social understandings.¹⁰⁷

Despite this work, in counter-narrative literature impairment is often forgotten as a reason for social subjugation. While Nelson mentions disability,¹⁰⁸ disabled people do not feature in her major case studies; and the dedicated issue of *Narrative Inquiry*, which forms the basis of the 'CCN debate' contains no discussion of counter-narratives developed by disabled people.¹⁰⁹ In addition, while various dominant groups are typically considered to be privileged by and within master narratives (such as white people, men, heterosexuals and those with wealth) absence of impairment is often omitted.¹¹⁰ There is, however, a body of academic work in which counter-narrative is used to examine impairment and disability. It is not possible to provide an exhaustive overview of this canon, but some key points are provided here for contextual purposes.

In these studies counter-narrative is often used as a tool to examine what it means to be disabled, or how disabled people understand their experiences. Smith and Sparkes, for example, examine how men with spinal cord injury devise narratives, including counter-narratives, to make sense of their situation and identity. There are

¹⁰⁵ The term 'autistic people' or 'autistic' (as a noun) rather than person/people with autism is commonly preferred by autistic people, for various reasons. Lorcan Kenny and others, 'Which Terms Should be Used to Describe Autism? Perspectives from the UK Autism Community' (2016) 20(4) *Autism* 442.

¹⁰⁶ Ian Hacking, 'How We Have Been Learning to Talk about Autism: A Role for Stories' (2009) 40 (3-4) *Metaphilosophy*, 499. For a discussion of Hacking's theory of the 'looping effect' that arises from the classification of groups of people, see: Ian Hacking, 'Between Michel Foucault and Erving Goffman: Between Discourse in the Abstract and Face-to-Face Interaction' (2004) 33(3) *Economy and Society*, 277. Hacking has examined how the labelling of people influences the way they think about themselves, and vice-versa. I am indebted to Dr Lucy Series for introducing me to his work.

¹⁰⁷ There are countless examples of disabled activists active on social media platforms. On Twitter in the UK see, as arbitrary examples @DrFrancesRyan, @LoomesGill, @AgonyAutie, @TanniGrey-Thompson, @perry_fleur, @SueBottCBE, @LindaBurnip, @RGPLizCrow, @TommyShakes, @RosemaryFrazer among hundreds, or thousands, of others. All on Twitter UK at <<https://twitter.com/twitteruk?lang=en>> accessed 26 July 2019.

¹⁰⁸ Nelson (n5) 161 and 182-183.

¹⁰⁹ In addition, a collection of articles that formed a special issue of the journal *Critical Psychology* in 2001 also lacked any articles relating to disability, although one article about women diagnosed with breast cancer was included. See: Fine and Harris (n57).

¹¹⁰ Solórzano and Yosso, for example, argue that a majoritarian story is 'one that privileges Whites, men, the middle and / or upper class, and heterosexuals', but do not mention disability or its absence. Solórzano and Yosso, 'Critical Race Methodology' (n3) 28.

also studies in which counter-narratives are used to consider the experience of mothering – as a disabled woman¹¹¹ or as the parent of a disabled child.¹¹² Studies have examined the counter-narratives of people with cognitive impairment,¹¹³ autism,¹¹⁴ and psychiatric survivors;¹¹⁵ and counter-narrative has also been used to consider how people with disfigurement ‘re-story’ themselves.¹¹⁶ Some work on disability and identity draws particularly on CRT. Hernández-Saca and Cannon use counter-narrative and CRT to consider the experiences of ‘Black and Brown people’ with a learning disability and a speech and language impairment in education settings,¹¹⁷ and Fiona Kumari Campbell touches on master and counter-narrative in work that uses critical race theory to examine the matter of ableism.¹¹⁸

Examples of the examination of activist counter-narratives also exist, although these are less common. Broderick and Ne’eman identify ‘autism as neurodiversity’ as a counter-narrative devised by the neurodiverse community to counter a dominant professional narrative of ‘autism as illness’.¹¹⁹ Trevisan examines how in the UK two loosely connected disability rights groups have used online ‘crowd-sourced advocacy’ to collectively develop counter-narratives to master narratives created in

¹¹¹ Anita Lappeteläinen and others, ‘“Celebrating Diverse Motherhood”: Physically Disabled Women’s Counter-Narratives to their Stigmatised Identity as Mothers’ (2018) 7(3) *Families, Relationships and Societies* 499.

¹¹² Pamela Fisher and Dan Goodley (n50); Nithi Muthukrishna and Hasina Ebrahim, ‘Motherhood and the Disabled Child in Contexts of Early Education and Care’ (2014) 21(3) *Childhood* 369.

¹¹³ Guðrún V. Stefánsdóttir and Rannveig Traustadóttir, ‘Life Histories as Counter-Narratives against Dominant and Negative Stereotypes about People with Intellectual Disabilities’ (2015) 30(3) *Disability & Society* 368; Rebecca A. Bitenc, ‘“No Narrative, No Self”? Reconsidering Dementia Counter-Narratives in *Tell Mrs Mill Her Husband Is Still Dead*’ (2018) 11 *Subjectivity* 128; Harter and others (n19).

¹¹⁴ Broderick and Ne’eman (n71).

¹¹⁵ Adame and Knudson (n9); Jasna Russo and Peter Beresford, ‘Between Exclusion and Colonisation: Seeking a Place for Mad People’s Knowledge in Academia’ (2015) 30(1) *Disability & Society* 153; Lauren Polvere, ‘Youth Perspectives on Restrictive Mental Health Placement: Unearthing a Counter Narrative’ (2011) 26(3) *Journal of Adolescent Research* 318. The term ‘psychiatric survivors’ was not universally used in the cited studies. Other terms were ‘mad people’ and ‘youth with emotional and behavioral challenges’.

¹¹⁶ Ursula Law and Ashley van Niekerk, ‘Restorying the Self: An Exploration of Young Burn Survivors’ Narratives of Resilience’ (2011) 21(9) *Qualitative Health Research* 1165; Tevya A. Hunter and others, ‘“Put Your Face to Face the World”: Women’s Narratives of Burn Injury’ (2013) 39 *Burns* 1588.

¹¹⁷ David Hernández-Saca and Mercedes Adell Cannon, ‘Interrogating Disability Epistemologies: Towards Collective Dis/Ability Intersectional Emotional, Affective and Spiritual Autoethnographies for Healing’ (2019) 32(3) *International Journal of Qualitative Studies in Education* 243.

¹¹⁸ Fiona Kumari Campbell, ‘Exploring Internalized Ableism Using Critical Race Theory’ (2008) 23(2) *Disability & Society* 151. Campbell does not seek to propose or examine ableism as a master narrative, or to study the output of the disability rights movement as a counter-narrative, but to use aspects of CRT to find new sites for the study of ableism.

¹¹⁹ Broderick and Ne’eman (n71).

the media of 'disability benefit claimants as "work shy" and a "drain" on society', producing campaign outputs which restored the agency and reconstructed the collective identity of disabled people.¹²⁰ In other work that does not deploy counter-narrative theory, but touches upon similar ideas, Beckett and Campbell argue that the social model is an 'oppositional device' that has enabled the disabled people's movement to develop a 'counter-rationality' or new 'regime of truth'.¹²¹

Various master narratives were found within this body of work. Among the most commonly identified was the 'medicalised narrative', or medical model. The medical model is set out in Chapter 2, section 3 and is discussed further immediately below. The power of the medical model as a master narrative, even if that term was not used, was widely acknowledged, and narratives of recovery and 'restitution' which reinforce it were commonly found in interview data.¹²² Another frequently cited master narrative, which also appeared in various forms, was the idea of 'deficit' or inadequacy.¹²³ Other master narratives included the 'scrounger' narrative noted above, the idea of a 'personal tragedy' (also discussed below) or victimhood,¹²⁴ 'risk-containment',¹²⁵ and disability as deviance.¹²⁶

The counter-narratives found within this literature were also diverse and ranged from simple 'alternative' stories to the activist counter-narratives discussed above. Authors conducting interviews with disabled people also identified stories that went 'beyond' counter-narrative. In their work with psychiatric survivors, for example,

¹²⁰ Trevisan (n62) 200.

¹²¹ Beckett and Campbell (n97).

¹²² Adame and Knudson (n9); Smith and Sparkes (n7); Fisher and Goodley (n50). The narrative of 'restitution' was originally proposed by Arthur W Frank, in his seminal work *The Wounded Storyteller* (University of Chicago Press 1995). In a work that has various parallels with counter-narrative theory, Frank distils the stories told by those experiencing illness into three general 'narrative types': the restitution narrative ("Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again", 77); the chaos narrative (essentially, "Life will never get better", 97); and the quest narrative, in which the person 'accept[s] illness and seek[s] to use it', 115. He does not position these as counter-narratives – indeed, he identifies the sources of the restitution narrative in particular as (among others) popular culture (stretching back to the Bible) – but rather examines how these narratives work as 'self-stories' for those who deploy them.

¹²³ Among others, Hernández-Saca and Adell Cannon (n117); Stefánsdóttir and Traustadóttir (n113); Eleni Theodorou and Katerine Mavrou, 'iConstruct: Virtual Disabilities in Online Settings' (2017) 32(4) *Disability & Society* 542; Lappeteläinen and others (n111).

¹²⁴ For example, Theodorou and Mavrou (n123); Muthukrishna and Ebrahim (n112); Bitenc (n113).

¹²⁵ Rose Leontini, 'Genetic Risk and Reproductive Decisions: Meta and Counter Narratives' (2010) 12(1) *Health, Risk & Society* 7.

¹²⁶ Theodorou and Mavrou (n123); Stefánsdóttir and Traustadóttir (n113).

Adame and Knudson discovered a narrative that bypassed the medicalised discourse and the concept of recovery and focused instead on the ability to enjoy life.¹²⁷ Research with disabled people therefore produced or identified different forms of narrative including counter-narratives and stories which simply focused on life experiences unconnected with disablement. Certain authors also had a particular focus on the relationship between the master and counter-narratives, with both Leontini¹²⁸ and Trevisan¹²⁹ questioning how far counter-narratives can fully break free of the master narratives they resist. Similarly, Barton considers how in one group certain counter-narratives themselves become dominant – and others unacceptable.¹³⁰

Various authors noted the importance of access to other disabled people or the ideas of the disabled people's movement if individuals were to be able to create counter-narratives or ways of being that successfully deviated from the medical model. Connors and Stalker identified the social model of disability¹³¹ as a counter-narrative which has the potential to enable disabled children to find a new 'language' to express their difference;¹³² and at least two individuals interviewed by Smith and Sparkes directly cited contact with other disabled people and the social model as a means of finding new ways of being.¹³³ Smith and Sparkes themselves identified the 'affirmative model' of disability, devised by Swain and French¹³⁴ as the model that provided individuals with the tools they needed to develop counter-narratives of their own.¹³⁵ Adame and Knudson emphasised the importance of peer contact for psychiatric survivors in 'break[ing] away' from the medical model and 'the language of psychiatry'.¹³⁶ In contrast, Smith and Sparkes questioned the extent to which the

¹²⁷Adame and Knudson (n9). Similarly, Fisher and Goodley (n50) found that while many mothers of disabled children sought diagnosis and treatment, others oriented themselves to narratives of parenting, rather than disability.

¹²⁸ Leontini (n125).

¹²⁹ Trevisan (n62), 200.

¹³⁰ Barton (n38). See section 2.1, above.

¹³¹ The social model of disability arose within the disabled people's movement as a means of countering the medical model. It, and its relationship to independent living, is explored and explained in Chapter 2.

¹³² Connors and Stalker (n28), 30.

¹³³ Smith and Sparkes (n7).

¹³⁴ John Swain and Sally French, 'Towards an Affirmation Model of Disability' (2000) 15(4) *Disability & Society* 569.

¹³⁵ Smith and Sparkes (n7).

¹³⁶ Adame and Knudson (n9), 174.

narratives used by disabled people were useful to them, and how far they were required instead by *non-disabled* people as a means of managing their own identity and fears of impairment. They suggest that disabled people may deploy ‘narratives of hope’ as a means of maintaining a relationship with the non-disabled world, implying that acceptance of a ‘damaged’ identity and operating within available master narratives may make it easier for disabled people to navigate the social world.¹³⁷ In relation to activist counter-narratives, the counter-narrative of autism as neurodiversity was identified as that of the ‘autistic community’ and its allies.¹³⁸ Most interestingly, in relation to this thesis, Trevisan gave a detailed account of how the individual ‘crowd sourced’ life stories of disabled people were woven into an effective ‘political’ counter-narrative.¹³⁹

Overall, this canon creates a level of insight into how disabled people use both master and counter-narrative to navigate their own lives. There is, however, limited work which examines the output of the UK disabled people’s movement as a counter-narrative. This thesis fills that gap and focuses on one of the core ideas produced by the movement. It conceptualises independent living as a central ‘activist’ counter-narrative of the movement, identifies the narrative repair it achieves, and considers what happens to it when it is brought into Welsh policy and legislation.

6. Counter-narrative and the disabled people’s movement

Although counter-narrative theory is rarely used to examine the experiences of disabled people, it is argued in this thesis that the development of activist counter-narratives is one of the defining features of the UK disabled people’s movement. In Chapter 2 it is stated that the movement is typically considered to have emerged with the creation of UPIAS, and that what distinguished UPIAS from earlier organisations of disabled people was the development of the social model of disability and the attendant reconceptualisation of narratives around disability. In this thesis the social

¹³⁷ Smith and Sparkes (n7), 1104.

¹³⁸ Broderick and Ne’eman (n71).

¹³⁹ Trevisan (n62), 200.

model is identified as an activist counter-narrative that forms the foundation of the movement. Various aspects of counter-narrative theory are seen its development and purpose. The network of early disabled activists and scholars identified social narratives which ascribed certain expectations, behaviours and roles to disabled people that had become what Finkelstein described as ‘normative assumptions’,¹⁴⁰ and Oliver as naturalised ‘facts’.¹⁴¹ These narratives – which are set out in Chapter 6, section 2 – and the behaviour and roles they created among both disabled and non-disabled people, were connected with notions of deficit and otherness and contributed to a situation in which exclusion from society and consequent restrictions on activity were considered natural and appropriate. Precisely in the manner identified by Nelson and Godrej, disabled activists came together, shared ideas, identified these harmful narratives and devised a new narrative – in the form of the social model – to counter them. Oliver explicitly set out to develop a model of disability that was ‘located within the experiences of disabled people themselves’ and which could connect disability with ideas of oppression.¹⁴² When exploring its distinction between disability and impairment, UPIAS had also identified oppression as a direct result of narrative identity construction.¹⁴³ Barnes and Mercer argue that the social model politicised disability and enabled the development of ‘a new discourse around citizenship and rights’ which established new identities for disabled people. In their words:

The emphasis shifted from ‘charity to rights’ and from social exclusion to inclusion with the replacement of a culture of dependence and pity by one based on acceptance as equal citizens.¹⁴⁴

¹⁴⁰ Finkelstein (n85).

¹⁴¹ Michael Oliver, *The Politics of Disablement* (Macmillan 1990) 80-81.

¹⁴² Ibid 10-11.

¹⁴³ ‘... it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.’ UPIAS, ‘The Union of the Physically Impaired Against Segregation and The Disability Alliance discuss Fundamental Principles of Disability’ (unpublished, 1975) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-fundamental-principles.pdf>> accessed 16 November 2016, pages unnumbered.

¹⁴⁴ Colin Barnes and Geof Mercer, *Independent Futures: Creating User-Led Disability Services in a Disabling Society* (Policy Press 2006), 37.

The social model performs a variety of functions that relate to identity repair. On a personal level it has provided individuals with new ways to think about themselves and disability, countering the problem of the 'infiltrated self'.¹⁴⁵ In the words of the disabled activist Liz Crow:

My life has two phases: before the social model of disability, and after it. ... This was the explanation I had sought for years. Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled - my capabilities and opportunities were being restricted - by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary! ...¹⁴⁶

On a wider level, and as Crow indicates, the social model provided the movement with solutions to the deprivation of opportunity which required action by society rather than themselves. In both cases, it operated as resistance and enabled collective action that was rooted in a narrative of oppression rather than deficit. The purpose and value of the social model as a tool to resist oppression and an 'oppositional device' has been the topic of academic literature as well as the disabled people's movement.¹⁴⁷

The development, purpose and content of the social model therefore feature ideas that are fundamental to counter-narrative theory. As the development of the social model was the feature that distinguished UPIAS from former organisations, and as

¹⁴⁵ Oliver describes in detail the requirement imposed upon disabled people to think about their circumstances – and themselves – in terms of damage, loss and tragedy. Michael Oliver, *Social Work with Disabled People* (Macmillan Press 1983).

¹⁴⁶ Liz Crow, 'Including All of Our Lives: Renewing the Social Model of Disability' in Colin Barnes and Geof Mercer (eds), *Exploring the Divide* (Disability Press 1996).

¹⁴⁷ Beckett and Campbell (n97) position and study the social model as an 'oppositional device', drawing from the work of Foucault and others. They state that the social model 'was born of resistance' and 'was the product of this resistance and enabled further resistance practices on the part of disabled people and their allies'. See also, Susan Peters, Susan Gabel and Simoni Symeonidou, 'Resistance, Transformation and the Politics of Hope: Imagining a Way Forward for the Disabled People's Movement' (2009) 24(5) *Disability & Society*, 543.

the model continues to play a fundamental part in disability activism in the UK, it can be stated that the movement itself is defined by and built upon the activity of counter-narrative development and attempts to reconceptualise identities. The revolutionary and emancipatory content of the social model, and its role in resisting and transforming narratives around disability and disabled people, have been comprehensively recognised and explored. How far the social model has succeeded in refuting master narratives is certainly a matter of debate. Shakespeare argues that building an identity around oppression *perpetuates* identities of separateness and victimhood, and that through doing so disabled people reinforce rather than counter their own oppression and lead discussion around disability into a negative frame.¹⁴⁸ A victim of oppression, however, elicits a different response than a victim of personal tragedy; and opens up distinct solutions for the problems of the infiltrated self and the deprivation of opportunity.

6.1. Independent living as a counter-narrative

In the UK context, independent living builds upon the movement's 'foundational' counter-narrative of the social model of disability to become a second or 'sister' activist counter-narrative. This section demonstrates the identity of independent living as a second activist counter-narrative. It draws in particular on a document authored by the disabled activist Simon Brisenden,¹⁴⁹ 'Independent Living and the Medical Model of Disability'.¹⁵⁰ This article demonstrates how independent living is imbued with elements that are identified in counter-narrative theory. It is one of many texts authored from within the movement that exhibits this connection and has been selected here for illustrative purposes as it brings many elements together particularly strongly.

¹⁴⁸ Tom Shakespeare, *Disability Rights and Wrongs Revisited* (2nd edn, Routledge 2014), particularly ch 5.

¹⁴⁹ Simon Brisenden founded Southampton Centre for Independent Living. Spectrum, 'Spectrum: Our History: 30 Years of Independent Living 1984-2014' (unpublished) <<http://spectrumcil.co.uk.gridhosted.co.uk/wp-content/uploads/2015/06/SPECTRUM-Our-History-30-Years-of-Independent-Living-Final-Copy-Email-Version.pdf>> accessed 24 January 019. Southampton Centre for Independent Living is now called Spectrum.

¹⁵⁰ Simon Brisenden, 'Independent Living and the Medical Model of Disability' (1986) 1(2) *Disability, Handicap & Society* 173.

Like the social model of disability, independent living was created as a form of resistance, pieced together by groups of marginalised and segregated individuals living on the fringes of society. The social model was developed first, by activists who intentionally took a theoretical approach to disability.¹⁵¹ Independent living arose among groups who were exploring practical responses to the constraints upon their lives, although theorising was also involved. Early writings of disabled activists – in the UK and in the US – illustrate how small groups of disabled people came together to share ideas and find new ways to think about their lives and identities, resisting attitudes and actions that they experienced as oppression. Hale Zukas, one of the students involved in the Berkeley movement, describes how the isolation of the disabled students created space in which they were able, for the first time, to exchange and explore ideas and experiences that questioned their circumstances, developing self-confidence and political awareness.¹⁵² In the UK similar groups emerged in which disabled people supported each other emotionally, practically and intellectually. In Le Court, for example, individuals involved in Project 81 were supported not only by each other, but by others who had formerly been involved in Le Court's history of resident resistance – who themselves were connected with individuals in UPIAS.¹⁵³ As with the social model, this coming together of minds and the consequent cross-fertilisation of ideas enabled the development of new narratives. A core distinction was that these were not precisely 'communities of choice'. While the social model was developed by geographically diffuse UPIAS network that self-selected for activism, independent living – in both the US and the UK – was created *within* the segregated institutions against which they rebelled. The act of forcing disabled individuals together created not just the anger and frustrations that led to the development of UPIAS and initiatives such as the Grove Road

¹⁵¹ Shakespeare (n148), 14-17.

¹⁵² Hale Zukas, 'The History of the Berkeley Center for Independent Living (CIL)' (Report for the State of the Art Conference, Berkeley Center for Independent Living, 1975) (*Independent Living Institute*, undated) <<https://www.independentliving.org/docs3/zukas.html> > accessed 12 July 2019. (undated) <<http://www.ilusa.com/articles/021300CILHistoryZukas.html>> accessed 7 December 2017.

¹⁵³ John Evans describes how individuals involved in Project 81 received support and advice from Peter Wade, a former resident of Le Court who had been involved in the residents' actions of the late 1960s with Paul Hunt. For Evans' description see: HCIL, 'Project 81: One Step On' (unpublished and undated) <<http://disability-studies.leeds.ac.uk/files/library/HCIL-one-step-on.pdf>> accessed 7 December 2017. For information about Peter Wade and the resident actions, see: Philip Mason, 'The Place of Le Court Residents in the History of the Disability Movement in England' (unpublished, 1990) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Mason-le-court-philip-mason.pdf>> accessed 25 May 2018.

scheme and Project 81, but also the flow of ideas and information that are, as Nelson, Godrej and others describe, essential to the development of a counter-narrative. The first act of subversion was therefore for individuals to convert their 'found' or imposed communities into communities of choice.

The Brisenden text demonstrates how independent living emerged as a complementary narrative to the social model and enabled disabled activists to explore new ways of living. Brisenden commented on the power of embedded ideas about disabled people. He referred to 'myths of disability', reproduced 'through books, articles, lectures and other forms of soothsaying and oracle',¹⁵⁴ and argued that these ideas had become entrenched as 'facts' and shaped by historical narratives. He identified the medical, or individual, model as the essential oppressive narrative. Like critical race theorists, he suggested that this model had the benefit of emerging from the 'expert' study of disability that purported to be objective and therefore 'neutral', and was consequently a particular danger:

The reality of the matter is that under the guise of objective scientific enquiry a particular image of disabled people is being fostered in the minds of the audience, and it is an image full of negative implications which are in themselves disabling.¹⁵⁵

Brisenden argued that a particular 'mythologised physical norm' acted as a measure against which disabled people were inevitably found wanting;¹⁵⁶ and that the medical model and its attendant narratives opened the door to exclusion and oppression in forms that disabled people had come to accept and reproduce.¹⁵⁷ He drew on the

¹⁵⁴ Brisenden (n150), 173. The idea of 'myths' of disability was also articulated by Paul Hunt, twenty years earlier. See Paul Hunt, 'A Critical Condition' in Paul Hunt (ed), *Stigma: The Experience of Disability* (Geoffrey Chapman 1966).

¹⁵⁵ Brisenden (n150), 175.

¹⁵⁶ Oliver is eloquent on the theme of the assumptions made by professionals in relation to disabled people, and the consequent development of damaging and inaccurate narratives and responses to individuals, particularly those who have recently acquired a disability. Oliver, *Social Work* (n145). Many other authors commented on the existence of a social 'able-bodied' norm. See, for example, Hunt (n154); AT Sutherland, *Disabled We Stand* (Souvenir Press 1981), Oliver, 'Social Policy' (n86).

¹⁵⁷ Many other disabled activist authors explore the matter of internalised damage to identity development. See, for example, Hunt (n154); UPIAS, 'Policy Statement' (1974, amended 1976, unpublished) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-UPIAS.pdf>> accessed 16 November 2016; UPIAS (n143); Sutherland (n156), Vic Finkelstein, Re-Thinking 'Care' in a Society Providing Equal Opportunities for All' (unpublished discussion paper

social model to describe society as the disabling factor and frame this as oppression, and argued for an opposing and resisting narrative, created by disabled people:

Our experiences must be expressed in *our* words and integrated into the consciousness of mainstream society, and this goes against the accumulated sediment of a social world that is steeped in the medical model of disability.¹⁵⁸

Brisenden concluded the article with a powerful description of independent living framed as a challenge to both the dominant social assumptions and the externally imposed and internally reproduced damage they cause. He called for what Nelson later conceptualised as ‘repair’ by disabled people of their narrative identity, and a reconceptualisation of the notion of independence as self-determination rather than self-reliance.

The Brisenden text therefore demonstrates how the development, the content and the role of independent living have much in common with core elements of counter-narrative theory. The existence of communities of marginalised individuals enabled the development of resistance and a radical reconceptualisation of the communities’ defining characteristics and circumstances. Brisenden recognised the existence of damaging master narratives that present as ‘facts’ or ‘truth’ and expressed what Nelson described as the ‘twin oppression’ of the deprivation of opportunity and the infiltrated self. In particular, he identified the requirement for a new narrative, created by the oppressed group, to express their experiences on their terms, and enable new identities to emerge, and cites independent living – then in its infancy – as that narrative. Brisenden looked to independent living to create and establish a new form of identity that would enable disabled people to break away from restrictive social norms and practices and forge their own way of being. In this format independent living was, and remains, a consciously devised activist counter-narrative.

commissioned by the World Health Organisation, March 1998)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-finkelstein2.pdf>>
accessed 18 November 2016.

¹⁵⁸ Brisenden (n150) 173-174, original emphasis. For similar calls, see also UPIAS (n143); UPIAS (n157).

7. The theoretical tools deployed within the thesis

This project does not seek to identify counter-narratives from interview, ethnographic or other forms of participant-focused data. Instead elements of counter-narrative theory are used to create a framework within which the construction of independent living in pre-existing groups of texts can be critically examined.

Elements are drawn from across counter-narrative literature, but in particular from the work of Nelson. In her discussion, Nelson sets out a number of aspects of counter-narrative theory that chime with ideas expressed within the disabled people's movement from its inception. In particular, Nelson examines the intersection of identity and agency and places particular focus on how the reclamation and redevelopment of agency contribute to the reconstruction of damaged identity – an element that is at the forefront of the discussion of independent living in the UK disabled people's movement. In addition, Nelson considers the intersection between everyday and activist counter-narratives that is integral to the development, and the understanding, of independent living as a counter-narrative. The particular theoretical elements deployed in this thesis are set out below.

7.1. Fragments

Nelson argues that both master and counter-narratives are assembled from what she describes as 'narrative fragments' – ideas, characters, themes and plots that are readily available in a particular culture and which can be crafted into stories that can be understood by social actors. In relation to master narratives, Nelson suggests that component fragments are capable of denoting a set of ideas and creating particular expectations because we are immediately familiar with their behaviour and connections.¹⁵⁹ Such narrative fragments are drawn from 'history, biography, film, fables, jokes' and 'proverbs, music, advertising slogans and other cultural

¹⁵⁹ Nelson (n5) 82-85 and 152.

artifacts',¹⁶⁰ but can also be 'products of our own personal histories'.¹⁶¹ Nelson submits that these narrative fragments iterate and reiterate themes, ideas and narratives in ensembles which develop, change and evolve in new directions in response to new information.¹⁶² This existence of master narratives as compilation of fragments enables them to evolve and to reinforce and bolster each other, but also renders them vulnerable to opposition and separation. Nelson suggests that counter-narratives can 'interfere with' or 'dislodge' parts of master narratives, enabling different ideas to take hold and different identities to be formed.¹⁶³ Nelson argues that when other fragments are pieced together, contesting narratives can be formed and new identities developed.

Drawing on Nelson's theorising, this thesis positions the themes that collectively construct independent living as its narrative fragments; and examines how these work together to perform an act of narrative repair by and for disabled people. It considers how these fragments emerged in everyday settings and were developed by the disabled people's movement and woven together into an activist counter-narrative that became a core political demand. It examines the work that these themes do to achieve the narrative reconstruction of the identity and agency of disabled people, the form of the identity and the agency that they create, and how they go about the work of dislodging and negating master narratives of disability. The thesis then traces these fragments into policy and legislative texts, examining their appearance (or non-appearance) in those contexts and the identity construction work that they do there.

7.2. Countering and compliance

Across the literature using counter-narrative theory there is significant discussion, and limited consensus, as to the relationship between master and counter-narratives. Certain authors have argued that a counter-narrative is defined by, and

¹⁶⁰ Ibid 158.

¹⁶¹ Ibid 83-84.

¹⁶² Ibid 158.

¹⁶³ Ibid 169.

can only exist in relation to, a master narrative.¹⁶⁴ Similarly, there are questions as to the extent to which counter-narratives oppose or are compliant with master narratives. In relation to everyday counter-narratives, Bamberg argues that as master narratives guide actions as well as constrain agency, they are never fully repudiated but must, at some level, remain intact to render new ideas intelligible.¹⁶⁵ Similarly, Leontini notes that in challenging master narratives, individuals borrow from the system of values that they espouse and thus carry ‘vestiges’ of those values.¹⁶⁶ Various authors note that what is a master narrative in one group may be a counter-narrative in another and vice versa;¹⁶⁷ and that a counter-narrative may itself become a master narrative.¹⁶⁸ Indeed, Nelson argues that to be optimally effective, a counter-narrative must become a master narrative ‘since success consists precisely in the counterstory’s becoming widely circulated and socially shared’.¹⁶⁹ Delgado argues that to be successful a counter-narrative must be non-coercive if the dominant group is not to increase resistance and reject it¹⁷⁰ (a point with which Nelson agrees¹⁷¹), suggesting – although not explicitly stating – that there must be some degree of contact, or even apparent or actual consensus, between these two narratives if the counter-narrative is to make headway.¹⁷²

Counter-narratives are therefore in a constant relationship of countering and compliance with the master narratives that they oppose. In this struggle, those resisting are required to avoid the difficulties that arise from acting on the ground occupied by the master-narrative. In his work on framing theory, Lakoff highlights the

¹⁶⁴ Michael Bamberg and Molly Andrews, ‘Introduction’ in Michael Bamberg and Molly Andrews (eds), *Considering Counter-Narratives: Narrating, Resisting, Making Sense* (John Benjamins 2004), x. See also Piekut (n20); Adame and Knudson (n9).

¹⁶⁵ Bamberg (n57).

¹⁶⁶ Leontini (n125). In relation to disabled activists, Trevisan (n62) found that individuals tended to view their own lives through the ‘lens’ of master narratives, while seeking to demonstrate how their own lives differed from the roles attributed to disabled people.

¹⁶⁷ For example, Harris, Carney and Fine (n56); Corinne Squire, ‘White Trash Pride and the Exemplary Black Citizen: Counter-Narratives of Gender, Race and the Trailer Park in Contemporary Daytime Television Talk Shows’ (2002) 12(1) *Narrative Inquiry* 155.

¹⁶⁸ Barton (n38).

¹⁶⁹ Nelson (n5) 157. Nelson notes that a counter-narrative that takes on an existence as a master narrative ‘never oppresses the individual it identifies’, but is silent as to whether a master narrative forged in this way must, by nature of its dominance, at some point oppress others.

¹⁷⁰ Delgado (n1).

¹⁷¹ Nelson (n5) 151.

¹⁷² In a parallel discussion in CRT, Bell (n54) argued that the ingroup will permit advantages for the outgroup to the extent that they also advantage the dominant interest or perpetuate the status quo.

dangers of engaging with – and using the language of – one’s rivals, suggesting that it invariably reinforces their message and enables them to control the discourse.¹⁷³ This is echoed in counter-narrative literature. Solórzano and Yosso, for example, argue that responding only to the master narrative increases that narrative’s dominance;¹⁷⁴ and Delgado argues that legal challenges inevitably face the difficulty of upholding the majoritarian social order.¹⁷⁵ Counter-narratives, by their nature, are required to do their work on the ground occupied by master narratives, arguably creating a risk of their neutralisation, damage or co-optation. This is a specific risk for activist counter-narratives that are obliged *explicitly* to engage with the narratives of the dominant group if they are to do their work effectively. In this thesis, therefore, there is consideration of whether and how the counter-narrative of independent living engages with the master narratives that it intends to refute, particularly master narratives connected with the concept of independence, and the implications of that engagement for its effectiveness.

7.3. Adjacency and collision

Where an activist counter-narrative becomes connected with government policy and law, countering and compliance are not the only critical relationships in play. In these circumstances, there are also relationships between the counter-narrative and the preferred narratives of the government – which may or may not be master narratives or which may be counter-narratives in their own right. Certain policy principles that a

¹⁷³ Lakoff (n84). In relation to independent living, Neil Crowther has also discussed the difficulty of the ‘swamp’ of ‘dominant public values and frames which we must carefully navigate in our journey towards our goals’. Neil Crowther, ‘From Independence to Interdependence – The Case for Reframing Disability Rights’ (Blogpost, 9 October 2015) <<https://makingrightsmakesense.wordpress.com/2015/10/09/from-independence-to-interdependence-the-case-for-reframing-disability-rights/>> accessed 18 March 2019. Crowther argues that adult social care in its entirety needs to be ‘re-framed’ – see: Neil Crowther, ‘Repositioning the Social Care Debate to Build Public and Political Support for More Effective Use of Existing Resources and Greater Investment in the Future’ (*In Control*, undated) <<http://www.in-control.org.uk/what-we-do/people-families/social-care-future/repositioning-the-social-care-debate-to-build-public-and-political-support-for-more-effective-use-of-existing-resources-and-greater-investment-in-the-future.aspx>> accessed 18 March 2019.

¹⁷⁴ Solórzano and Yosso, ‘Critical Race Methodology’ (n3) 32, citing Lisa Ikemoto, ‘Furthering the Inquiry: Race, Class, and Culture in the Forced Medical Treatment of Pregnant Women’ in A Wing (ed), *Critical Race Feminism: A Reader* (New York University Press 1997), 136.

¹⁷⁵ Delgado (n1) 2428.

government seeks to promote may be similar to ideas contained in a particular activist counter narrative, or may be wholly distinct. If the engagement between an activist counter-narrative and policy or legislation is to be explored and understood, there must therefore be consideration of these relationships and their implications.

This matter is not explored in existing counter-narrative literature. This thesis therefore extends counter-narrative theory to establish a framework that enables consideration of the relationships between a counter- and a policy narrative, or particular elements of these. These relationships fall into two broad groups: those in which the aims of counter- and policy narratives are broadly or apparently analogous; and those in which there is conflict. In this thesis, the term 'adjacency' is introduced to refer to the first of these categories of relationships, in which there are similarities between the counter-narrative and the policy narrative. The terminology of 'overlapping' narratives is not used, as this suggests some form of intentional or incidental dovetailing or consensus between the counter- and the policy narratives. In contrast, adjacent narratives are those in which the same or similar ideas occur, but may not have the same origin, be considered in the same way, or be deployed for the same purpose or intended outcomes. There is therefore an *apparent* harmony between narratives which may not be expressing the same idea. The second category of these relationships is that in which elements of the policy and counter-narratives are, or appear to be, oppositional. In this thesis, the terminology of 'collision' is introduced to signal such relationships. In this category, fragments or ideas found in the counter-narrative may conflict partially or entirely with those in policy. If the counter-narrative is to be drawn into policy and legislation, this collision must therefore either be confronted and de-fused or obscured.

7.4. Linguistic reclamation

Counter-narrative literature is imbued with the notion of repair, or of reclamation, particularly in relation to the narrative repair of the self and identity. Writing in the feminist context, Godrej places reclamation at the centre of counter-narrative development and the understanding of self, and extends this to the notion of *linguistic* reclamation, arguing that the subversion of dominant discourses requires a

'refashioning' of dominant language. In this process, the reclamation or 'salvaging' of certain words and phrases is a necessary stage in the countering of (in particular) the infiltrated self. Godrej envisages this as a form of ownership of or authority over language:

We reclaim words and phrases so that we refashion their meanings to correspond to our particular goals. We rescue or salvage them from their earlier—often derogatory— meanings so that they have the authority of our ownership behind them. ... This specifically linguistic reclamation is a tool for disarming the power of a dominant group to control one's own and others' views of oneself, to categorize oneself or one's group in a totalizing way.¹⁷⁶

Linguistic reclamation, and the matter of oppressed groups reclaiming derogatory labels (such as 'queer' or 'crip') is a specific area of research which cannot be covered by this thesis. However, the counter-narrative of independent living requires to some extent a reformulation of – or counter-narrative to – the notion of independence (see Chapter 8). The thesis therefore extends to the consideration of the linguistic reclamation of independence as an element of the independent living counter-narrative, and the implications of this for its effectiveness.

8. Conclusion

This chapter demonstrates that the disabled people's movement was founded upon the activity of counter-narrative creation and that independent living is a critical activist counter-narrative for the movement. It suggests that it is necessary to understand how an activist counter-narrative is impacted by its incorporation into policy and legislative texts. Following a chapter that sets out the methods used in the study, the remainder of this thesis examines the development, use and impact of independent living as a counter-narrative and the impact on that counter-narrative of its absorption into social care policy and law in Wales. The second part of the thesis prepares the ground for the study of independent living in the policy context. It

¹⁷⁶ Godrej (n27) 111.

demonstrates how independent living is constructed and how it acts as a counter-narrative that subverts master narratives, with the aim of remodelling the identity of disabled people, reclaiming agency and rejecting internalised damage. The final part of the thesis examines how independent living and independence are constructed and used within policy and legal texts in the Welsh context, using the analytical framework of adjacency and collision. There is consideration of the impact on the counter-narrative of this absorption, and the implications of this for the exercise of narrative repair attempted by the disabled people's movement.

Chapter 5: The methods used in the project

1. Introduction

The thesis positions independent living as an activist counter-narrative and considers the work it does within the disabled people's movement and how it is deployed within policy and law. The particular emphasis of the project lay in this latter aspect, and the examination of the impact on independent living of its absorption into policy and legal discourse. The project therefore used naturally occurring documents as data. It examined how independent living was constructed in different sets of texts, with datasets comprising documents from the Anglo-British disabled people's movement, the Welsh disabled people's movement and the Welsh Government.

This took counter-narrative analysis into new areas. With few exceptions, previous studies using counter-narrative theory had examined how individuals had developed and used counter-narratives as a means of navigating their everyday lives and understanding their identities. In these studies interviews were the most typical data. Only a small number of studies used naturally occurring documents as data, including a handful which explored the deployment of an activist counter-narrative emerging from a social movement.¹ However, none of these deployed methods that could be replicated or approximated for this study, which required the comparison of the concept of independent living in different contexts. It was therefore necessary to develop and apply a method that enabled the examination and comparison of independent living in different sets of documents so that the implications arising from

¹ The most notable of these were the study by Trevisan into the online output of disabled activists and the examination by Acevedo and others of the countering of master narratives by the Nation of Islam. Filippo Trevisan, 'Crowd-Sourced Advocacy: Promoting Disability Rights through Online Storytelling' (2017) 6(2) Public Relations Inquiry 191, 200; Gabriel A Acevedo, James Ordner and Miriam Thompson, 'Narrative Inversion as a Tactical Framing Device: The Ideological Origins of the Nation of Islam' (2010) 20(1) Narrative Inquiry 124.

similarities and distinctions of these constructions could be considered. This chapter sets out the method that was devised and the underpinning rationale.

2. How counter-narrative theory is used in the study

What was needed for this study was a systematic method that could both assess the importance placed on certain of the narrative fragments that compose independent living and enable the interpretation of the content of those fragments, including an examination of their development and the relationships between them. It was necessary for the method to be systematic and transparent. This would enable the examination of the same aspects of independent living in each set of documents, and valid comparisons.

Inspiration was sought from other projects that used naturally occurring documents as data, particularly projects using critical discourse analysis (CDA). CDA has much in common with counter-narrative theory. In discourse analysis, the term 'discourse' is used to refer to 'a particular way of talking about and understanding the world',² and any given discourse is considered to construct the social world in such a way as to infuse certain ideas with the status of 'common sense' or typically accepted 'facts' that perpetuate a particular ideology.³ In this format, discourse has much in common with master narratives. Indeed, across counter-narrative literature there are various examples of the terms 'narrative' and 'discourse' being used interchangeably,⁴ sometimes intentionally.⁵ CDA is characterised by consideration of how language produces and reproduces power and social inequalities⁶ and how identity is formed through discourse.⁷ Texts are considered as 'sites of struggle' over meaning in which

² Marianne Jørgensen and Louise Phillips, *Discourse Analysis as Theory and Method* (Sage 2002), 1.

³ John Flowerdew and John E Richardson, 'Introduction' in John Flowerdew and John E Richardson (eds), *The Routledge Handbook of Critical Discourse Studies* (Routledge 2018).

⁴ Talbot and others, for example, variously use the terms 'master narrative', 'dominant discourse' and 'master claims' interchangeably. Jean Talbot et al, 'Affirmation and Resistance of Dominant Discourses: The Rhetorical Construction of Pregnancy' 1996 6(3) *Journal of Narrative and Life History* 225-251.

⁵ Kölbl aligns and equates the term 'master narrative' with 'discourse', before intentionally using the terms synonymously. Carlos Kölbl, 'Blame it on Psychology!?' (2002) 12(1) *Narrative Inquiry* 29.

⁶ Anssi Peräkylä and Johanna Ruusuvuori, 'Analysing Talk and Text' in Norman K Denzin and Yvonna S Lincoln (eds), *The Sage Handbook of Qualitative Research* (5th edn, Sage 2018), 672.

⁷ Flowerdew and Richardson (n3).

'differing discourses and ideologies' contend for supremacy and dominance.⁸ This project similarly considered how meaning was contested within and around a particular counter-narrative. Like counter-narrative theory, CDA is generally considered to be a theoretical standpoint, rather than a method,⁹ embracing a variety of approaches.¹⁰ Some studies rely solely on qualitative analysis.¹¹ In others researchers combine qualitative with quantitative approaches,¹² sometimes as a means of countering criticisms that CDA approaches can be too subjective.¹³ A number of studies use coding to enable the identification and exploration of core ideas in data.¹⁴ Particular inspiration was taken from these latter groups of studies.

In this project independent living was envisaged as a counter-narrative constructed by the disabled people's movement upon a series of themes that operate as its narrative fragments. Taking a set of representative texts from across the Anglo-British movement, a detailed coding system was created that uncovered these various themes and enabled their study across the different sets of texts. Using this coding structure as a basis, the project examined how these narrative fragments

⁸ Ruth Wodak, 'What CDA is About – A Summary of Its History, Important Concepts and Its Developments' in Ruth Wodak and Michael Meyer (eds), *Methods of Critical Discourse Analysis* (Sage 2001), 11.

⁹ Norman Fairclough, 'Critical Discourse Analysis as a Method in Social Scientific Research' in Ruth Wodak and Michael Meyer (eds), *Methods of Critical Discourse Analysis* (Sage 2001); Paul Baker and others, 'A Useful Methodology Synergy? Combining Critical Discourse Analysis and Corpus Linguistics to Examine Discourses of Refugees and Asylum Seekers in the UK Press' (2008) 19(3) *Discourse and Society* 273; Lilja suggests that '[d]iscourse analysis can be used both as a theoretical perspective and as a research method'. My Lilja, 'Chapter 7. Narrative Stories and Discourses in an Interview with a Former Amphetamine User' (2013) 48(13) *Substance Use & Misuse* 1360, 1361.

¹⁰ See for example, those outlined in John Flowerdew and John E Richardson (eds), *The Routledge Handbook of Critical Discourse Studies* (Routledge 2018).

¹¹ Fairclough (n9) for example, engages in detailed descriptions of texts that draw from Halliday's model of Systematic Functional Linguistics.

¹² For example, Veronika Koller and Paul Davidson, 'Social Exclusion as Conceptual and Grammatical Metaphor: A Cross-Genre Study of British Policy-Making' (2008) 19(3) *Discourse and Society* 307; Clive Seale, 'Cancer Heroics: A Study of News Reports with Particular Reference to Gender' (2002) 36(1) *Sociology* 107.

¹³ Paul Baker, 'Acceptable Bias? Using Corpus Linguistics Methods with Critical Discourse Analysis' (2012) 9(3) *Critical Discourse Studies* 247.

¹⁴ For example, Seale (n12); Charlotte Burck, 'Comparing Qualitative Research Methodologies for Systemic Research: The Use of Grounded Theory, Discourse Analysis and Narrative Analysis' (2005) 27 *Journal of Family Therapy* 237; Paul Chaney and Daniel Wincott, 'Envisioning the Third Sector's Welfare Role: Critical Discourse Analysis of 'Post-Devolution' Public Policy in the UK 1998–2012' (2014) 48(7) *Social Policy & Administration* 757; Sayers and others, 'Speeding Up or Reaching Out? Efficiency and Unmet Need as Policy Priorities in Wales' (2017) 16(3) *Journal of Language and Politics* 388 (pre-publication copy provided to author). This last study examined a Welsh Government document that was also explored in this PhD project.

appeared within the texts, how they conducted the work of the narrative repair of the identity and agency of disabled people, and how they dislodged elements of the master narratives identified by activists. These narrative fragments were then examined in texts emerging from the disabled people's movement in Wales, to establish whether there were distinctions in the construction of independent living in that context.

The same fragments were then traced into the policy texts authored by the Welsh Government. Consideration was given to whether the fragments deployed by the disabled people's movement continued to exist in the policy texts, or whether they disappeared or were replaced by other fragments. Where they continued to exist, it was possible to examine whether they were modified, constructed, used or understood in different ways in different contexts, and whether new meanings or different emphases were allocated to them. In this way, conclusions could be drawn as to whether the various narrative fragments of independent living remained extant, or whether they were altered or re-developed in the policy context. In addition, as independent living required the 'linguistic reclamation' of the language of independence, references to independence were also coded to establish whether it was deployed in a 'reclaimed' or 'original' sense within each group of texts.

3. An overview of the methods

Three separate datasets of texts were developed for this project. These were:

- Texts from the Anglo-British disabled people's movement relating to independent living and social care, before, during and after devolution of responsibilities to Wales (the '**Anglo-British DPM dataset**'). This included a small sub-set of 'dissenting' texts.
- Texts from the disabled people's movement in Wales (the '**Welsh DPM dataset**');
- Policy texts from the Welsh Government relating to social care, independent living and disability (the '**WG dataset**').

The same research stages were deployed for each of these datasets in turn. These are outlined immediately below, with detailed information on the dataset formation, coding and analysis provided in the remainder of the chapter.

The analysis of these datasets was followed by a doctrinal analysis of the Social Services and Well-being (Wales) Act 2014 and associated regulations and guidance to establish whether and how certain fragments of independent living had been inserted into law. This was assisted by a study of various background documents, including explanatory memoranda, the Record of Proceedings of the National Assembly for Wales, ministerial statements and others, which shed light on the reasons for the treatments of particular fragments.

The stages that were carried out on the documents from each of the datasets were:

3.1. Reading the texts

Each of the selected documents was read in detail in date order. Notes were made on immediate impressions arising from the text in relation to the content in general as well as themes and ideas and purposes connected to independent living and independence.

3.2. Coding the texts

The documents were imported to NVivo and placed into separate NVivo projects for documents from the Anglo-British disabled people's movement, the Welsh disabled people's movement and the Welsh Government. The texts were re-read and searched for the phrase 'independent living'.¹⁵ Extracts where this phrase appeared were coded. All the codes were inductively devised and reflected the narrative fragments found within the texts. The essential coding structure was developed through the work on the Anglo-British DPM dataset and then applied to the other

¹⁵ Computer searches were not used other than to ensure that references had not been missed. References to independent living, living independently and independence were found through searching for the root 'independ'.

datasets, with certain codes added or removed according to the ideas expressed within the other dataset texts.

A separate coding structure was devised for the references to independence in the texts. These related to the matter of the linguistic reclamation of this idea and were deductively applied (see section 5.2.2, below).

As the Welsh DPM dataset was small, two stages of coding were applied. First, all the references to independent living were coded as set out above. Once certain codes had been selected for examination and analysis, the whole texts were searched for these narrative fragments and coded accordingly. This provided further information on how these fragments were constructed in the Welsh DPM documents. The analysis in Chapter 7 indicates where the broader context is under consideration, rather than the sections of text in which independent living was explicitly mentioned.

The full texts in the WG dataset were also searched and coded for the fragments that had been selected for examination, in addition to the coding of the ideas of independent living and independence. This was to establish whether the fragments of independent living had made their way into policy separately from discussion of independent living itself and, if so, how they were constructed and treated. As the *Framework for Action on Independent Living* (2013) was a critical document in relation to the treatment of the counter-narrative of independent living in Welsh Government policy, the whole document was treated as a statement of the Welsh Government's understanding and construction of independent living and coded for the relevant fragments.¹⁶ In this document there was no separation of the extracts in which the phrase 'independent living' appeared.

¹⁶ Welsh Government, 'Framework for Action on Independent Living' (2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018.

3.3. Analysis of the narrative fragments

Each code represented a narrative fragment of independent living. The codes were examined and certain codes were selected for examination. Attention was paid to the content of the extracts within each code, the relationship between the codes and the numbers of extracts that fell into each code. During the analysis there was also reference back to the wider texts, to capture information about the narrative fragment that existed in the texts but was not directly connected to the language of independent living.

4. The formation of the datasets: The sources of the data and the selection of texts for analysis

A criticism commonly levelled at methods of textual analysis, and particularly methods used in critical discourse analysis, is that data selection can be biased, and driven by a desire to arrive at preconceived conclusions.¹⁷ The selection of documents to be included in the datasets was certainly pivotal. In any research project, the selection of data will have the single biggest impact on the results obtained. Given the concerns about potentially 'cherry-picked' data,¹⁸ Flowerdew and Richardson suggest that it is necessary to provide a clear and detailed explanation of what the data comprise and how they are collected.¹⁹ This section provides that explanation and sets out the broad selection criteria that were applied. Information on the number of texts, the dates of each dataset and authors is provided in Table 1 at the end of this section, and a full list of the documents in each dataset is contained in Appendix 1.

¹⁷ Baker (n13) citing: H G Widdowson, 'The Theory and Practice of Critical Discourse Analysis' (1998) 19(1) *Applied Linguistics* 136; A Partington 'Corpora and Discourse, a Most Congruous Beast' in A Partington, J Morley and L Haarman (eds), *Corpora and Discourse* (Peter Lang, 2004); D Orpin 'Corpus Linguistics and Critical Discourse Analysis' (2005) 10(1) *International Journal of Corpus Linguistics* 37.

¹⁸ Baker (n13).

¹⁹ Flowerdew and Richardson (n3) 7.

4. 1 Documents from the Anglo-British disabled people's movement

Owing to the nature of the disabled people's movement, there were challenges in relation to the selection of relevant texts. The Anglo-British disabled people's movement has historically comprised a large, informally connected, collection of disparate organisations and individuals, who write and speak sometimes on behalf of a particular group, but sometimes in relation to individual experiences and opinions.²⁰ These authors produce a large output of texts on a wide range of topics. It was therefore necessary to obtain a representative sample and avoid risks pertaining to generalisations made from small numbers of documents²¹ or repeated authorship. Ultimately, the sample needed to be 'relevant to or representative of the phenomenon of interest',²² large enough to produce useful information and to provide reasonable evidence for the claims made and small enough to be manageable in the available timescale.

The dataset therefore needed to contain documents by an appropriate authorship that covered relevant themes and ideas but also provided a 'snapshot' of the movement from its inception. It is noted in Chapter 2 that in recent years a movement of 'sick and disabled' people has also emerged. This project focused on texts authored by activists following in the tradition of the earlier movement, as it was here that discussion of independent living was more typically found. Many authors in the 'sick and disabled' people's movement, for example, focused on narratives of austerity rather than 'care', writing in particular about the benefits or 'welfare' system.²³ Overall, 37 documents dated between 1966 and 2015 were included in the

²⁰ For a detailed discussion of this, see Jane Campbell and Mike Oliver, *Disability Politics: Understanding Our Past, Changing Our Future* (Routledge 1996), particularly chapters 4 and 5.

²¹ Linda Wood and Rolf O Kroger, *Doing Discourse Analysis: Methods for Studying Action in Talk and Text* (Sage 2000).

²² *Ibid* 78.

²³ See, for example, the response of the group 'Broken of Britain' to the Joint Committee Inquiry into the Right to Independent Living. Broken of Britain, 'Written Evidence Submitted by the Broken of Britain (IL 67, 29 April 2011). Published in Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (12 December 2011) 364-371 <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 6 July 2019. The narrative output of this movement has been studied using counter-narrative theory, in which master narratives of 'welfare dependency', 'skivers' and 'scroungers' were identified. Trevisan (n1).

dataset, including six papers presented at one conference. The selection criteria for these documents were as follows:

4.1.1. Access

Documents were sourced from the public domain, without the need for requests for access to disabled people's organisations. The reason for this was that as the research identified independent living as an activist counter-narrative – that is, one which intends to contest master narratives that form social opinions and relations – documents that were accessible to the public had a particular role in conducting that challenge. All the documents were therefore sourced online.²⁴

4.1.2. Authorship

Only documents written by disabled people and organisations controlled by disabled people were included. This reflected the absolute principle of the UK disabled people's movement that it is formed of and controlled by disabled people.²⁵ Given the looseness of the disabled people's movement and the large number of documents produced by it, certain further criteria for the authorship of documents were imposed. These are set out in Appendix 2.

4.1.3. Timespan

The dataset included texts that dated from the beginnings of the movement to the time of analysis to enable the origins and development of fragments of independent living to be studied.²⁶ As far as possible, selected documents were evenly spread throughout the existence of the movement, to avoid potential clustering around

²⁴ Many of the documents were sourced from the Disability Archive at the Centre for Disability Studies, University of Leeds. This is a repository of documents about disability, including a large number of historical and activist documents. Leeds University Centre for Disability Studies, 'The Disability Archive' (undated) <<https://disability-studies.leeds.ac.uk/library/>> accessed 12 July 2019. One draft consultation document was requested from the Welsh Government.

²⁵ See Chapter 2, section 2.

²⁶ See Chapter 2, section 2 for discussion as to the origins of the movement.

particular events or incidents. Suitable documents from around 2010 onwards were relatively difficult to source and fewer were therefore included.²⁷

4.1.4. Subject matter

All the documents contained some level of discussion of – or references to – independent living or independence. As the main focus of the study was independent living in adult social care policy and legislation, priority was given to documents that contained discussion of either the overall aims and purpose of independent living or independent living in relation to social care or other support structures. Exceptions were made for early documents, prior to the rise of independent living.

4.1.5. 'Dissenting' works

Within the disabled people's movement, the discussion about independent living has involved multiple different opinions, including 'dissenting' views, which were markedly different from an otherwise broad consensus on certain ideas and values. These indicated that there were struggles for meaning around independent living within the movement. A number of these texts were included in the dataset to enable the examination of this plurality of content. It should be noted that individual texts were considered to dissent, not the output of specific authors.

4.1.6. Types of documents and their purpose

Many kinds of documents were available, ranging from unofficial 'raw' texts such as presentations or blogposts on personal experiences to more formal documents such

²⁷ At the time of the compilation of the dataset the most recent document in the Disability Archive to be tagged with the keyword 'independent living' was dated 2011. Of documents available from DPO websites containing analysis of independent living, many were authored by coalitions which included organisations that were not controlled by disabled people, rendering them unsuitable for inclusion in this study. An exception was made for documents produced by Disability Rights UK and Disability Wales – these organisations counted non-DPOs among their members, but identified themselves as DPOs. Disability Rights UK requires at least 75 per cent of its trustees to be disabled people and at the time of writing had a majority of staff who were disabled. See DRUK, 'Our Organisation' (undated) <<https://www.disabilityrightsuk.org/about-us/our-organisation>> accessed 21 February 2018. Disability Wales describes itself as: 'a membership organisation run by disabled people' **and has a Board of Directors who all identify as disabled people. See Disability Wales, 'About' (undated) <<http://www.disabilitywales.org/about/>> accessed 12 July 2019.**

as academic articles, reports and consultation responses. Texts from across this range were included to enable the capture of different ideas.

4.2. Documents from the disabled people's movement in Wales

The disabled people's movement in Wales is explored in Chapter 3, section 4, where it is noted to be less developed than the Anglo-British movement. There was a very small pool of texts applicable only to Wales from which a dataset could be drawn. There are few active DPOs in Wales and of these organisations, few published substantive texts of relevance to this project online. Responses from certain organisations to the consultation on the Social Services and Well-being (Wales) Bill were available on the Welsh Government website.²⁸ Documents from both Disability Wales and All Wales People First were also available and included. As both the pool of authorship and the available documents were limited in Wales, one document produced by the chairperson of Grwp Mynediad Arfon / Arfon Access Group (AAG) was also included. While this individual is not known to be disabled, information about AAG and the language of the text indicated that there was a strong connection with the disabled people's movement and that the AAG could be considered an 'ally'.²⁹ This meant a loosening of the criteria on authorship, but increased both the number of documents and the variety of authorship in the Welsh dataset. In the thesis all comments from AAG are identified.

As a result of these constraints, the Welsh dataset was small, comprising six documents. It was also repetitive both in terms of the authors and the type of documents included. In particular, there was a heavy reliance on documents

²⁸ The response by Dewis CIL was available and relevant but was not included as the bulk of this text was reproduced, largely verbatim, in the Disability Wales partner organisation response which also covered a number of other areas. The Disability Wales document was therefore selected.

²⁹ *The document indicated* a close alliance with the definition of 'independent living' drafted by Disability Wales, concerns about the misappropriation of the language of the disabled people's movement and a rejection of the language of 'care' in favour of the language of support (for discussion on this point see Chapter 6, sections 2 and 4.4. For discussion of who might be considered allies of the movement, see Chapter 2, section 2.

produced by Disability Wales. The documents also spanned a narrow timeframe, from 2011 to 2016.

4.3. Documents from the Welsh Government

Extensive online searching uncovered only one policy or strategy document by the Welsh Government that pertains specifically to social care – the consultation document prior to the development of the Social Services and Well-being (Wales) Act 2014. To obtain a meaningful number of documents for study, this dataset therefore extended to policy texts which covered the wider remit of social services or which pertained to disabled people in the wider context. Two documents relating to social care were also included that formed legally binding guidance.³⁰ Seven policy documents were finally selected for study.

³⁰ These documents were Welsh Assembly Government and NHS Cymru, 'Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care' (2002) <<http://www.wales.nhs.uk/sitesplus/documents/829/WAG%20-%20Creating%20a%20Unified%20and%20Fair%20System%20for%20Assessing%20and%20Managing%20Care.PDF>> accessed 21 June 2019; and Welsh Assembly Government, 'Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance Wales 2004' (2004) <<http://www.wales.nhs.uk/documents/direct-payment-policy-e-merge.pdf>> accessed 21 June 2019. Both these documents were issued under s7(1) of the Local Authority Social Services Act 1970, which requires local authorities to act under the guidance of the relevant government department. They are therefore formal guidance and binding rather than persuasive. Case law indicates that if a local authority may only depart from such guidance if it has good and identified reason to do so. *R v Islington LBC ex p Rixon* (1997) 1 CCLR 119.

Table 1: The content of the datasets

Dataset name	Dataset content	Dates of texts	Authors (with number of texts from that author)
Anglo-British DPM dataset	<p>Texts from the Anglo-British disabled people's movement before, during and after devolution.</p> <p>(37 texts)</p>	1966-2015	<p>Paul Hunt (1), Union of the Physically Impaired Against Segregation (UPIAS) (2), Allan Sutherland (1), Ken Davis (3), Vic Finkelstein (3), Simon Brisenden (1), Mike Oliver (2), British Council of Organisations of Disabled People (1), Colin Barnes (2), Hampshire Centre for Independent Living (1), Stewart Bracking (1), Maggie Davis (1), Anne Rae (1), Nasa Begum (1), Dennis Killin (1), John Evans (2), Philip Mason (1), Jenny Morris (3), Gerry Zarb (1), Peter Beresford (1), Jane Campbell (1), Debbie Jolly (1), Disability Rights UK (2), Inclusion London (2), Tom Shakespeare (1).</p> <p>These included dissenting texts by: Ken Davis (1), Vic Finkelstein (1), Tom Shakespeare (1).</p>
Welsh DPM dataset	<p>Texts by authors in the disabled people's movement in Wales</p> <p>(6 texts)</p>	2011-2016	<p>Disability Wales / Anabledd Cymru (3), Disability Wales / Anabledd Cymru on behalf of partner organisations (1), All Wales People First (1), Vin West for Arfon Access Group (author not known to be disabled) (1).</p>
WG dataset	<p>Policy texts by Welsh Government</p> <p>(7 texts)</p>	2002-2017	<p>Welsh Government / Llywodraeth Cymru (formerly Welsh Assembly Government / Llywodraeth Cynulliad Cymru)</p>

5. Coding the texts: The development of the coding structure and the coding process

5.1. The development of the coding structures

Extracts of the documents were placed into separate principal codes for either 'independent living' or 'independence', depending on what language was used. If both terms were used in the same extract, they were coded to both principal codes. All the references in each code were then coded into child nodes, according to the meaning and purpose of the reference to independent living or independence in the text.

Many narrative fragments of independent living were found, explored and coded. These related to matters such as the content, purpose and enablers of independent living, its history and origins, threats and opportunities, and its contact with government policy. As the coding process continued, codes were grouped together into parent and grandparent codes according to the wider or general themes they expressed. Some remained child nodes directly under the principal code of 'independent living'. The coding structure is set out in Appendix 3. The code book is provided in Appendix 4.

5.2. The coding process

In all the documents the initial stage of coding was restricted to extracts where the actual words 'independent living' or 'independence' / 'independent' / 'independently' appeared. The sections of text that were coded were the relevant sentence/s with the immediate surrounding context where this assisted in understanding the meaning of the sentence. Detailed information as to the coding process is provided in Appendix 5. Annotations were frequently made during the coding process, to note why a particular code had been applied and thoughts on the content of the extract. The process of coding involved a 'back and forwards' approach, in which earlier

coding was re-examined and revised as new codes emerged within and across the datasets through the inductive process.

5.2.1. The coding of independent living

Multiple coding was freely undertaken in relation to independent living as many extracts contained multiple ideas. Codes were applied if a theme was referenced implicitly as well as explicitly. Coding to implicit themes was restricted to avoid the potential pitfalls of the coding becoming both too subjective and so wide as to be meaningless. More information on this is provided in Appendix 5.

5.2.2. The coding of independence

The coding of independence was restricted to codes that related solely to the linguistic reclamation of independence. Following the study of independent living in the Anglo-British DPM dataset texts, three codes were created to reflect the discussion of different aspects of independence. These were applied to extracts in which references to 'independence' occurred. The three codes were:

- Uses of 'independence' that were synonymous with the idea of 'independent living' or which related to the idea of personal self-determination;³¹
- Uses of 'independence' to refer to self-reliance;
- Uses of 'independence' that were unclear in relation to this distinction, or which could be said to relate to both self-reliance and self-determination.

³¹ Self-determination and independent living are not the same, and one or other idea was relevant in each dataset. For example, in the Anglo-British DPM dataset, there were many references to independence that were synonymous with independent living but none that referred separately to self-determination. In contrast, in the earlier Welsh Government documents, in which independent living was not yet assimilated, there were various references to independence that were connected with self-determination but none that related to independent living. The relevant code is indicated in the coding scheme provided in Appendix 3 and made clear in the analysis.

As the purpose of this coding exercise was to establish whether a reference related to either the 'typical' or the 'reclaimed' understanding of independence (or the master or counter-narrative) there was no double or multiple coding.³²

In addition, certain codes arose inductively from the texts. These included:

- Discussion of the language or meaning of independence;
- Discussion of independence as it was presented in government policy;³³
- Independence from home or parents, or an institutional setting;
- Young people moving into adulthood;
- Independence in a title (for example, 'Personal Independence Payment' or 'PIP').

References that fell into these themes were not coded to any of the three codes relating to the reclamation of independence. In the case of governmental discussion of independence, this was because such extracts did not reflect the authors' own use of this language. In relation to extracts coded as discussion of the meaning of independence, it was because the extracts specifically covered the matter of language reclamation and therefore needed to be examined separately. The notion of independence from home, parents, or an institutional setting, or moving into adulthood, were also distinct ideas – they embraced both the ideas of self-determination and self-reliance but also extended beyond these.

Only references to the independence of disabled people were coded. References to the independence of individuals in other groups, or which referred to something being non-partisan or non-aligned (such as an independent advocate, or an independent agency) were not coded.

³² If the meaning of 'independence' could not be considered to refer unequivocally to either independent living / self-determination or self-reliance, it was placed in the 'ambiguous' code.

³³ This included discussion of how the government understood or presented the idea of independence and quotes from government sources.

6. The analysis of the coded extracts

The coding in relation to independent living was extensive. Multiple codes emerged and the majority of extracts were coded multiple times. In the final analysis, the codes that were analysed in detail were those containing narrative fragments that were directly connected to identity and agency of disabled people.³⁴ These were not necessarily the most heavily used codes, but they related specifically to the matter of identity construction and repair that is central to the purpose of a counter-narrative. Other codes referred to, for example, threats to independent living, future needs for independent living, independent living as a creation of the disabled people's movement, or the impact of resources. Ideas reflected in all the codes informed the analysis.

As with the coding process, the first set of findings to be examined were those pertaining to the Anglo-British DPM dataset texts. As independent living is a concept devised by the disabled people's movement, both in the UK and internationally, it was necessary to establish what was originally intended by independent living, how it was originally constructed, and what narrative fragments existed within it before any narrative fragments of independent living could be examined in the other datasets. After the analysis of the Anglo-British DPM dataset documents, the texts were examined in the same order that they were coded: dissenting texts, Welsh DPM texts and Welsh Government policy texts.

It was not appropriate in this analysis to rely on the numbers of references ascribed to particular codes other than as a general indicator of their prominence. In all the datasets the number of references in any particular code might be a result of many things such as a particular author's writing style, a focus by an author on a specific theme, or simply the differing lengths of the texts and the wider subject matter of some documents over others. Overall, the *consistency* of the references across the texts (that is, the number of texts in which a theme appeared), rather than the number of references overall, was considered a more reliable indicator that a matter

³⁴ See Chapter 6, section 4.

was of particular importance within the disabled people's movement. Such consistency was an indicator of interest from a cross-section of authors and also suggested that those matters might be of importance to the readership. For these reasons, while the numbers of references were considered as an indicator of interest in a particular idea, no further significance was placed on numerical analysis.

In the interpretive analysis of the extracts, attention was paid to many things. The most important was the content of fragments – whether, for example, a fragment such as choice was presented as a choice between things, choice more generally, or an entirely abstract idea. While the formation of the datasets did not allow for extensive temporal analysis, the evolution of fragments within each dataset was examined where possible. Consideration was given as to how particular ideas had originated, whether they were transferred from other ideas to independent living, whether they were connected to an everyday or an activist counter-narrative or whether they made the transition from one to another. Attention was also paid to silences within the texts, or what remained unsaid.

During the analysis the coded extracts were read in their contexts, with reference back to the wider texts. Reference was also made to the notes made on the initial readings of the documents and the annotations on the extracts made during the coding process.

7. Reflections on the benefits and limitations of the methods

The methods devised and applied in this project enabled a highly systematic analysis of the construction of independent living that could be carried through different sets of texts, enabling the tracing of narrative fragments through different settings and valid comparisons between the constructions of independent living in these settings. This paved the way for new understandings of how independent living operates as a counter-narrative and the impact on the content and operation of that counter-narrative when it was transported into different contexts.

Certain limitations arose from the methods. The most significant was that the detailed analysis, particularly in relation to the Anglo-British DPM texts, was conducted on small sections of text. The extracts of any one text that were coded typically amounted to a small proportion of the text in question. However, this project was not intended to be an analysis of the *texts* created by certain groups of authors, but of the construction of independent living and the treatment of independence *within* those texts. The sections of texts that were subjected to detailed examination were those that had been systematically identified as containing information on narrative fragments of independent living that were relevant to the study of independent living as a counter-narrative. These were considered both alone and in their wider textual, social and historical contexts. No claims or assumptions could be, or were, made in relation to the content of the texts more widely, other than where further information was drawn on those fragments from the broader texts. These occasions are indicated in the analysis in Chapters 6 and 7.

Because of the constraints on this project, a more extensive selection of documents from the disabled people's movement could not be read and coded in the time available. Hundreds of documents exist for potential study. This difficulty was offset by the use of the selection criteria outlined above, to ensure that the sample of texts was representative of those emerging from the movement in relation to the subject matter covered by this thesis. It is, of course, possible that a different selection of texts would produce different findings. The purpose of this project was to conduct an illustrative, transparent and replicable study of independent living in different contexts, and the findings and analysis pertain to the datasets that were selected.

8. Conclusion

While this project was underpinned by counter-narrative theory, the nature of the study meant that there were no 'pre-existing' methods available that could be borrowed or adapted and applied to it. The methods that were deployed were therefore created for the project and based upon methods and rationales used within textual analysis, particularly critical discourse analysis. In devising the methods, the

aim was to enable a systematic examination of the narrative fragments of independent living in particular sets of texts and uncover 'hidden' information.

As with any form of research, certain questions and ideas, particularly those relating to coding, arose through immersion in the data, and there was initially a process of exploration, in which different methods, including some deployed in projects using corpus linguistics were investigated. Various pilot projects were undertaken, using both smaller sections of the final datasets and additional datasets of texts that were ultimately discarded. The methods that were finally used were those which gave the greatest insight into the counter-narrative of independent living in relation to the research questions posed in this study.

Part II: Independent Living as a Counter- Narrative

Chapter 6: Fragments of independent living in the Anglo-British texts

1. Introduction

This second part of the thesis examines how independent living works as an activist counter-narrative to accomplish the work that Nelson described as ‘narrative repair’. The data are the texts from the Anglo-British disabled people’s movement from its inception to the current day and those emerging from the disabled people’s movement in Wales.

This part comprises three chapters. This chapter examines the Anglo-British DPM texts. It identifies the core fragments of independent living and considers how these repair the identity and agency of disabled people to counter what Nelson describes as the ‘deprivation of opportunity’ and the ‘infiltrated self’.¹ The chapter begins with a section that sets out the master narratives that independent living resists, and then examines the fragments of independent living that relate to identity and agency. The following chapter follows these fragments into the texts from the Welsh DPM dataset and examines the construction of independent living in that context. The subsequent and final chapter in this part introduces the key broad areas of potential adjacency and collision between independent living in both the Anglo-British and Welsh DPM texts and those of the Welsh Government, and complications and risks that may arise from the use of the language of ‘independence’. That chapter establishes the framework for the examination of the fragments in the Welsh policy and legislative texts.

¹ Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Cornell University Press 2001). See Chapter 4, for discussion of Nelson’s work.

2. The master narratives

This section sets out the master narratives identified by authors of the texts in the Anglo-British DPM dataset, including some dissenting texts, and the identities and roles they ascribe to disabled people. It draws in particular from a number of early texts, written in the 1970s and 1980s, although later texts are also cited. In these texts, certain authors discussed the expectations, roles and attitudes to which disabled people felt subject. Other authors focused more on the policies that derived from and perpetuated these narratives, and the impact of these on disabled people. The counter-narrative of independent living – and, indeed, that of the social model of disability – were therefore developed within a young and evolving disabled people’s movement as a resistance to *both* the master narratives *and* disabled people’s experiences arising from policies enabled by them. Both groups of authors used similar language, referring to, for example, oppression and dehumanisation.²

The medical, or the individual, model of disability was identified as a critical master narrative.³ It was strongly present in the texts, although it was sometimes referred to obliquely, by implication or by a different name. Oliver argued that the medical model itself was underpinned by or flowed from the idea of a ‘personal tragedy’ and could equally well be named ‘personal tragedy theory’.⁴ Other authors also discussed the idea of ‘personal tragedy’, and it formed a critical master narrative in its own right, existing separately from and together with the medical model.⁵ Both the personal tragedy narrative and the medical model held the concept of deficit at their centre – the narrative of a personal tragedy conveys the idea that the disabled individual has

² See, for example, UPIAS, ‘Policy Statement’ (1974 amended 1976) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-UPIAS.pdf>> accessed 16 November 2016; Simon Brisenden, ‘Independent Living and the Medical Model of Disability’ (1986) 1(2) *Disability, Handicap & Society* 173.

³ It is noted in Chapter 4, section 5 that in studies using counter-narrative to explore issues related to disability the medical model was also typically identified as a core master narrative.

⁴ Mike Oliver, ‘Social Policy and Disability – Some Theoretical Issues’ (1986) 1(1) *Disability, Handicap & Society* 5, 6. In this article, Oliver likewise argued that the social model might be called ‘social oppression theory’.

⁵ The earliest allusion to a narrative of ‘personal tragedy’ came in the earliest document, authored by Paul Hunt in 1966. Paul Hunt, ‘A Critical Condition’ in Paul Hunt (ed), *Stigma: The Experience of Disability* (Geoffrey Chapman 1966) 145-146.

suffered a catastrophic loss in relation to a social norm,⁶ and the medical model focuses on individual ‘defect’ and its impact on the person. Master narratives of deficit were therefore fundamental to the construction of the identified ‘disabled identity’. Other narratives could be broadly categorised as connected to marginalisation or ‘othering’ – an activity that notions of deficit make possible or justifiable. As is demonstrated in Chapter 4, the ideas of deficit and otherness are identified by various theorists as central to the effective operation of master narratives.

In relation to the idea of deficit, authors identified disabled people being categorised as stupid,⁷ helpless,⁸ pathetic,⁹ dependent or ‘weak and needy’,¹⁰ passive,¹¹ ‘moral’ failures – with connotations of evil¹² – and unsuccessful and inadequate¹³ to the extent of uselessness.¹⁴ Hunt connected ‘uselessness’ in particular with a lack of economic productivity.¹⁵ UPIAS considered that the narratives of deficit had a direct bearing on a person’s agency and personal integrity, identifying a social view that disabled people had no capacity for decision-making.¹⁶ Ideas related to deficit were very strongly expressed. Authors used the language of inferiority,¹⁷ waste,¹⁸ or forms

⁶ Oliver, ‘Social Policy’ (n4) 4; BCODP, ‘Comment on the Report of the Audit Commission “Making a Reality of Community Care”’ (August 1987) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/BCODP-report-of-audit-comm.pdf>> accessed 19 November 2016, para 4.1.

⁷ AT Sutherland, ‘Disabled We Stand’ (Souvenir Press 1981) 82.

⁸ Ibid 83; Brisenden (n2) 175; Oliver, ‘Social Policy’ (n4) 10, citing A Shearer, ‘A Framework for Independent Living’ in: A Walker and P Townsend (eds), *Disability Rights in Britain* (Martin Robertson 1981).

⁹ Brisenden (n2) 174.

¹⁰ Sutherland (n7) 76.

¹¹ Brisenden (n2) 174.

¹² Hunt (n5) 156.

¹³ Brisenden (n2) 173

¹⁴ Hunt (n5) 149.

¹⁵ Ibid 148-149. Hunt describes disabled people being considered as ‘parasites on the economic body’ (149). This was a matter that was of particular interest to UPIAS. One of the campaigning issues for UPIAS was the debate between UPIAS and the Disability Alliance on the matter of a disability income. See, UPIAS, ‘Policy Statement’ (n2); UPIAS, ‘The Union of the Physically Impaired Against Segregation and The Disability Alliance discuss Fundamental Principles of Disability’ (1976) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-fundamental-principles.pdf>> accessed 16 November 2016.

¹⁶ UPIAS, ‘Policy Statement’ (n2) 13.

¹⁷ Hunt (n5) 158.

¹⁸ UPIAS, ‘Policy Statement’ (n2) para 6. Hunt referred to ‘rejects’. Hunt (n5) 158.

of sub-humanity¹⁹ to describe either the narratives or their resulting experiences. Ideas of heroism or transcendence were also connected to this narrative – disabled people were permitted to be courageous – and even inspirational – if their personal deficit was overcome.²⁰ Narratives of otherness were also articulated in various ways. Hunt used the words: ‘other’,²¹ ‘deviant’²² and ‘different’ or ‘unlike the normal’,²³ and Brisenden argued that disabled people were fundamentally seen as ‘abnormal’,²⁴ to the extent of being deemed a ‘different and unfortunate species of being’,²⁵ A particular aspect of this was a narrative that reduced disabled people to their impairment, simultaneously reducing their individuality or humanity and emphasising both their ‘otherness’ and their ‘deficit’.²⁶

Master narratives of dependence were also discussed. As the movement developed, the language of ‘vulnerability’ was also identified.²⁷ Various authors noted that the systems of the welfare state required disabled people to focus on inability and need in order to obtain support;²⁸ and were constructed as being in need of protection and ‘care’.²⁹ These master narratives were considered to create and underwrite social policies and practices that in turn manufactured an *actual* dependency among disabled people.³⁰ Authors argued that this served both as a means of social control

¹⁹ Ibid paras 2 and 6. Hunt suggested that disabled people may be considered ‘only half alive, only half human’. Hunt (n5) 147. Brisenden stated that disabled people were seen to be ‘flawed in some aspect of their humanity’. Brisenden (n2) 173.

²⁰ Hunt (n5) 148. In a more recent text that was not included in the dataset, Oliver and Barnes suggest that disabled people are constructed as either ‘less than human’ or ‘more than human’ but are never permitted simply to be people alongside non-disabled individuals. Oliver M and Barnes C, *The New Politics of Disablement* (Palgrave Macmillan 2012).

²¹ Hunt (n5) 152.

²² Ibid 150 and 152.

²³ Ibid 146.

²⁴ Brisenden (n2) 175.

²⁵ Ibid 174.

²⁶ Ibid; Hunt (n5); UPIAS, ‘Policy Statement’ (n2).

²⁷ Vic Finkelstein, ‘Re-Thinking “Care” in a Society Providing Equal Opportunities for All’ (discussion paper commissioned by the World Health Organisation, March 1998) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-finkelstein2.pdf>> accessed 18 November 2016, (pages unnumbered); Gerry Zarb, ‘Independent Living and the Road to Inclusion’ in C Barnes and G Mercer (eds), *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004) 197-198; Jenny Morris, ‘Independent Living and Community Care: A Disempowering Framework’ (2004) 9(5) *Disability & Society* 427, 431.

²⁸ For example, Morris (n27) 431. A similar point was made by UPIAS (n15) as long ago as 1976 in relation to the proposal by the Disability Alliance for a national disability income.

²⁹ BCODP, ‘Comment on the Report of the Audit Commission’ (n6) para 3.1.

³⁰ For example UPIAS, ‘Policy Statement’ (n2); Brisenden (n2); BCODP (n6); Colin Barnes, ‘Cabbage Syndrome’: *The Social Construction of Dependence* (Falmer Press 1990); Ken Davis, ‘The Disabled

and to support the needs of certain groups, particularly professionals³¹ and large charities.³² Dependency was seen as a narrative in itself,³³ but also as a degrading social condition that emerged from and was intertwined with the narratives of incapacity, paternalism, and otherness.³⁴ To an extent, however, dependency – in terms of a need for support in daily living – was also seen as a likely or inevitable and natural part of the disabled condition.³⁵ In this form, dependency was also connected to the idea of interdependence and the fact that *all* people, regardless of impairment or its absence, are dependent upon each other for their physical and social needs.³⁶ The authors therefore had a complex relationship with dependency. Dependence was envisaged as a master narrative that created narrative damage and as a social and political outcome of other master narratives, but was also expressed as both a natural and an imposed state for disabled people *and* a natural element of the broader human condition.

People's Movement: Putting the Power in Empowerment' (paper for seminar at Sheffield University 1996, updated 1998)

<<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/DavisK-davis-empowerment.pdf>> accessed 18 November 2016. This theme was also explored by authors in a number of texts that were not included in the dataset. In his seminal text *The Politics of Disablement*, Oliver argued that economic, political and professional practices and discourses had established social identities for disabled people which were mired in reliance, helplessness and passivity and which combined to produce infantilised and dependent individuals, isolated from ordinary society with limited educational and employment opportunities. Michael Oliver, *The Politics of Disablement* (Macmillan 1990).

³¹ BCODP, 'Comment on the Report of the Audit Commission' (n6); Davis, 'Empowerment' (n30).

³² Davis, 'Power' (n30). See also Jenny Morris, 'The Meaning of Independent Living in the 3rd Millennium' (text of a talk delivered at University of Glasgow Centre for Disability Research, May 1999) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/morris-The-meaning-of-independent-living-in-the-new-millennium.pdf>> accessed 18 November 2016.

³³ Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation, 2011).

³⁴ Sutherland (n7); Davis, 'Power' (n30); Morris, 'Meaning of Independent Living' (n32).

³⁵ UPIAS, 'Policy Statement' (n2); Sutherland (n7) quoting interview with Micheline Mason; BCODP, 'Comment on the Report of the Audit Commission' (n6). In one of the dissenting texts, Shakespeare describes these two forms of dependence as 'physical' and 'social' dependency. Tom Shakespeare, *Help: Imagining Welfare* (Venture Press 2000) (Chapter 4: 'Helpful').

³⁶ Oliver, 'Social Policy' (n4); BCODP, 'Comment on the Report of the Audit Commission' (n6); Stewart Bracking, 'Independent/Integrated Living - A Brief Overview' (presentation at BCODP seminar 'Making Our Own Choices', 1992)

<<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019; Davis, 'Power' (n30). This theme was explored in more detail in texts that were not included in the dataset. The most detailed discussion was in: Vic Finkelstein, 'Attitudes and Disabled People: Issues for Discussion' (World Rehabilitation Fund 1980) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-attitudes.pdf>> accessed 4 February 2019. It is also seen in Michael Oliver 'Disability and Dependency, in L Barton (ed), *Disability and Dependency* (Falmer 1989).

In the texts, there was deep frustration with narratives of 'charity', which were seen to entrench both narrative and actual dependency³⁷ and to obscure an alternative discourse of entitlement to support.³⁸ Master narratives of paternalism were also identified and both charity and paternalism were considered to underwrite the workings of the welfare state.³⁹ There was equal distaste for the language of 'care', which was seen to be connected with these master narratives. The word 'care' itself was often used as a generic term to refer to the services or support provided by councils and other authorities⁴⁰ (albeit often placed in inverted commas).⁴¹ From an early stage, however, 'care' was rejected as being connected to paternalistic narratives of 'vulnerability' and being 'looked after' and to social relationships of control. The 1987 BCODP text argued that 'care' was a narrative of non-disabled people, imposed upon those with impairments, which created dependency and furthered the interests of different groups. BCODP related 'care' to the medical model and argued instead for 'support', a distinction that was also made by others.⁴² The difference between care and support was critical and related specifically to control of or by the disabled person. Care was associated with control over the disabled person by others – including family and other informal carers – while support was associated with the disabled person having the management of their assistance and life.⁴³ In a dissenting text, Shakespeare quoted Richard Wood as saying:

Disabled people have never demanded or asked for care! We have sought independent living which means being able to achieve maximum independence and control over our own lives. The concept of care seems to

³⁷ UPIAS, 'Fundamental Principles' (n15) (pages unnumbered); Brisenden (n2) 175; Vic Finkelstein (writing as James Thorpe), 'A Question of Choice' (in UPIAS, 'Disability Challenge' Issue 1, May 1981)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-A-Question-of-Choice.pdf>> accessed 18 November 2016.

³⁸ Sutherland (n7); HCIL, 'HCIL Papers 1990: Independent Living' (1990)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-hcil.pdf>> accessed 16 November 2016 (pages unnumbered).

³⁹ 'State charity' is discussed in particular in UPIAS, 'Fundamental Principles (n15). 'Welfare paternalism' is discussed by Morris (n33) in one of the latest documents in the dataset.

⁴⁰ For example, UPIAS, 'Policy Statement' (n2); Oliver, 'Social Policy' (n4); Davis, 'Power' (n30).

⁴¹ See, for example, Brisenden (n2).

⁴² Davis, 'Power' (n30).

⁴³ See, in particular, Finkelstein, 'Re-thinking Care' (n27); Morris, 'Meaning of Independent Living' (n32).

many disabled people a tool through which others are able to dominate and manage our lives.⁴⁴

The primary function of the identified master narratives was seen to be to service the needs of dominant social groups. Sutherland argued that the medical model and the 'personal tragedy' narrative served to emphasise the ingroup's 'normality' and create feelings of wellbeing among non-disabled people.⁴⁵ Hunt argued that the need to 'other' arose from the ingroup's fear of illness and mortality,⁴⁶ and the desire to reassure oneself of their own superiority. In general, authors agreed that the composite result of the master narratives was oppression.⁴⁷ Sutherland extended this to a wider discussion on oppression, arguing that the direct purpose of 'role conditioning' created by dominant discourse was a more generalised maintenance of powerlessness among certain social groups, including disabled people, from whom weakness and dependence are required if dominance among others is to be maintained.⁴⁸

In addition to non-disabled people in general, two social 'ingroups' were particularly discussed – the 'expert' on disability, in the form of medical and other professionals working in the field of disability, and large charities run by non-disabled people. The absolute rejection by the movement of the role of charities 'for' disabled people is discussed in Chapter 2, section 2. Non-disabled professionals were strongly criticised for a number of reasons including objectifying disabled people,⁴⁹ failing to consider or accept disabled people's understandings of their own situation (and impairment and disability more widely),⁵⁰ imposing their own values on disabled people,⁵¹ and, overall, assuming direct and indirect control over disabled people's decisions and lives.⁵²

⁴⁴ Shakespeare, 'Help' (n35) 63. Richard Wood is a former Director of BCODP. In this text Shakespeare himself uses the term 'care' in the generic sense referred to above.

⁴⁵ Sutherland (n7).

⁴⁶ Hunt (n5). A similar purpose was identified by Smith and Sparkes in relation to the restoration narrative described by Frank. See Chapter 4, section 5.

⁴⁷ Ibid; UPIAS, 'Policy Statement' (n2); UPIAS, 'Fundamental Principles' (n15); Brisenden (n2).

⁴⁸ Sutherland (n7).

⁴⁹ Brisenden (n2) particularly at 174.

⁵⁰ Sutherland (n7); Brisenden (n2).

⁵¹ UPIAS, 'Policy Statement' (n2) para 15.

⁵² Ibid para 14; Sutherland (n7).

Overall, activists within the disabled people's movement argued that these narratives *both* created a profoundly damaged identity for disabled people *and* underpinned social policies that damaged their identities, lives, activities and opportunities, causing the practical situations which independent living was developed to challenge. The narratives of the medical model, personal tragedy, deficit, incapacity, otherness and 'care' enabled social responses that segregated, excluded and institutionalised disabled people, enabled professionals and others to assume control over them and effectively denied them fundamental human qualities, such as self-determination, respect and dignity.

3. The content and evolution of the texts

On reading, coding and analysing the texts it was found that certain texts contained discussions of independent living in relation to the identity and agency of disabled people that were particularly vivid. These were typically those authored in the earlier days of the disabled people's and independent living movements and those authored by individuals. These two aspects often overlapped, in that the majority of the later texts, particularly from 2010 onwards, were written by organisations. This vividness was felt to be for two main reasons. Early texts needed to express the content of independent living, its impact and its purpose – both in terms of resistance and narrative repair – clearly and in detail. Texts written by individuals were often 'raw' and expressed resistance in less moderate terms than those written by organisations, reflecting both the greater latitude to individuals writing on their own behalf, and the different purpose of such writing. Texts written by individuals, particularly in the early days of the movement, were often informal, expressing individual and deeply personal experiences and intended to act as a 'call to arms' to other disabled people and as statements of protest. The purpose of texts written by organisations, in contrast, was often dialogue with government and other agencies, with the texts required to indicate engagement as well as resistance. Organisational texts were also often responses to external papers, which were aimed at audiences beyond disabled people.

It was also noted that the later documents, from around 2011 onwards, made fewer references to independent living. This was partly due to the selection of documents, certain of which were either responding to specific pieces of policy or legislation, or focused on a wide range of matters of importance to disabled people.⁵³ In later documents, there was often a particular emphasis on rights under the UNCRPD. It appeared that in the later documents, the idea of independent living was considered to be better understood and incorporated, to an extent, in external agendas, and therefore required less explanation. This shift in the dataset, and the way in which independent living was discussed, indicated the evolution of the disabled people's movement from one of informality, with strategies of opposition and individual struggle, to one that had more frequent engagement and contact with formal structures, including government.

4. The narrative fragments of independent living

Nelson argues that the purpose of a counter-narrative is to enable groups of people who are subjugated to oppression, marginalisation or exclusion to reframe identities which master narratives distort and thus enable them freely to exercise their agency. The fragments that were examined in this study were therefore those which pertained to the identity and agency of disabled people, namely the experience and outcomes of independent living for disabled people and how these are achieved. Appendices 3 and 4 provide details of all such themes that were found in the texts. Of these, certain themes stood out in terms of their purpose in identity construction, the number of references made to them and their importance within the texts.

Certain of these larger fragments fell into two 'clusters', in each of which there was both a correlation of ideas between the component themes and a tendency for these themes to appear together, in the same extracts of text. These could be broadly

⁵³ The Inclusion London 2013 Manifesto, for example, contained a statement of vision and principles that did not mention independent living, although this was set out as the second priority demand. Inclusion London, 'Disabled People's Manifesto: Reclaiming Our Futures' (2013) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UK-Disabled-People-s-Manifesto-Reclaiming-Our-Futures.pdf>> accessed 2 January 2017.

identified and named as 'self-determination' (including the fragments coded as choice, control and self-determination), and 'community life' (including inclusion, participation, an active life and community or non-institutional living). Each of these clusters developed a particular form of agency for disabled people, named here as: 'personal agency' and 'social agency'. Running through these were the further fragments of equality and rights which were central to a further cluster of fragments relating to citizenship. This section explores each of these groups of thematic fragments before examining the core enablers of independent living that were articulated in the texts. A table providing the numbers of references to the core fragments explored in this chapter is in Appendix 6.

4.1. Personal agency: choice, control and self-determination

Self-determination was primarily expressed through the ideas of choice and control, although other ideas including self-determination and self-responsibility were also discussed.⁵⁴ Choice and control were connected to independent living consistently throughout the documents until the most recent text in the dataset,⁵⁵ and were among the most frequently discussed outcomes of independent living.⁵⁶ They were closely connected. The majority of the references to choice or control appeared in the same extracts, largely through the repeated use of the phrase 'choice and control', which was particularly deployed in later texts.

Of these two ideas, in the relevant extracts control was referenced more frequently and was on occasion strongly emphasised, particularly in the earlier texts:

⁵⁴ Of these ideas, self-determination was the most commonly discussed. Self-determination was only separately coded if this idea was specifically referenced (see Appendix 5). It was separately or additionally connected to independent living in 22 extracts.

⁵⁵ In the Anglo-British DPM dataset, choice and control were first related to independent living in the 1984 dissenting text by Ken Davis, in which they were negatively discussed (see Chapter 8, section 3.1). In the non-dissenting texts, they first occurred in the 1986 Brisenden document (n2).

⁵⁶ There were 61 references to control and 56 to choice in the extracts.

independent living pivots on the right to control our lives without being oppressed, intimidated or abused in any way. CONTROL is the central component of independent living (original emphasis).⁵⁷

This echoed a strong emphasis on control in the earliest texts from the movement. Prior to the development of independent living, UPIAS had placed emphasis on both choice and control, with control expressed as the primary idea.⁵⁸

Choice and control were closely connected to the early struggles of disabled people, particularly in relation to services and support, and specifically a need for personal assistance.⁵⁹ Again, control was particularly emphasised:

A central element of 'independent living' is personal assistance and, in particular, having direct access to the cash which gives freedom to hire and fire assistants who carry out duties determined by and under the control of the disabled person him or herself.⁶⁰

⁵⁷ Nasa Begum, 'Independent Living, Personal Assistance and Disabled Black People' (presentation at BCODP seminar 'Making Our Own Choices', 1992) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019, 51, original emphasis.

⁵⁸ The 'fundamental principles of disability' identified by UPIAS (n15) were: disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people. This point is also made by Zarb, 'Road to Inclusion' (n27) 192, citing Vic Finkelstein, 'A Personal Journey into Disability Politics' (presentation, Centre for Disability Studies, University of Leeds, 7th February 2001).

⁵⁹ Personal assistance is explained and discussed in Section 4.4 below.

⁶⁰ Maggie Davis, 'Personal Assistance – Notes on the Historic' (paper at BCODP seminar, 'Making Our Own Choices', August 1992) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019. See also, 'The particular issue which currently receives most attention, and so is most closely associated with the phrase [independent living], is that of control over the Personal Assistants required to overcome individual physical and/or intellectual limitations. Indeed it has been suggested that the degree of control granted is a direct measure of the quality of "independent living"'. HCIL, 'HCIL Papers' (n38) pages unnumbered. And: 'When they set up the Berkeley CIL it was all about control. It was about disabled people taking control of the services that they wanted.' John Evans, 'The Role of Centres of Independent/Integrated Living and Networks of Disabled People' (paper at BCODP seminar, 'Making Our Own Choices', August 1992) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019, 60. And '...once they had control over [support resources] they were able to regain control over their lives. Choice and control over the way assistance is provided is therefore at the heart of the disabled people's movement's definition of independent living.' Morris, *Rethinking* (33), 11.

Inherent in the struggle for choice and control, but particularly the latter, was a demand for the transference of control from those in authority to disabled people.

'...the most important thing is having control and choice over ones own life, because when one has this we are involved in all the decisions that affect our lives. This means we have the power and control, it does not rest in the hands of the authorities.'⁶¹

Extracts from the early texts referenced choice and control over basic everyday activities and also the idea of having general choice and control over one's own life:

If we are talking about independent living we should have the right to eat what we want, when we want, how we want, and with whoever we want.⁶²

Independent living is a lot of things but for me it is about: 'disabled people taking control of their lives and changing their lives.'⁶³

The conceptualisation of both choice and control swiftly evolved into more abstracted, generalised principles, particularly with the repeated use of the phrase 'choice and control'. This phrase was first connected to independent living in the

⁶¹ John Evans, 'Understanding Our Past and Controlling Our Future' (presentation at NCIL Forum, 12th July 2001)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/evans-Understanding-our-Past-and-Controlling-our-Future.pdf>> accessed 18 November 2016, 4. Earlier in this document (page 2), Evans states: 'The system sometimes operates in a way forcing compromise upon the individual. It is the way that the service provider can maintain control. Independent Living practice enables disabled people to challenge the system, hence the power struggle'. See also: 'Disabled people see the new battle ground as the struggle between the narrow definition of "independent living" imposed by the servants of society and that of our own broader concept of "independent living" as the enabling of equal opportunities. The right to Personal Assistance and control over it is seen by disabled people as being the way to enable equal opportunity.' HCIL, 'HCIL Papers' (n38) pages unnumbered. And: 'In the new millenium the Independent Living Movement needs to reach out to people who are in residential care, to people who, while they are living in their own homes, are yet institutionalised within them by services over which they have no control.' Morris, 'The Meaning of Independent Living' (n32) 24.

⁶² Begum (n57) 53.

⁶³ Evans, 'The Role of CILs' (n60) 63. See also: 'The present focus of attention is control over the assistance necessary in tasks associated with everyday life, i.e. getting up, going to bed, personal hygiene, eating, shopping, cooking and cleaning.' HCIL, 'HCIL Papers' (n38) pages unnumbered.

DPM dataset documents in 1992.⁶⁴ From 2004 it appeared in the extracts repeatedly, and was used almost as a mantra or ‘slogan’ to denote the fundamental elements of independent living.⁶⁵ The importance of the fragments of choice and control was emphasised by extracts in which these themes were positioned as the underpinning values of independent living, to the extent that Morris referenced them as the definitional elements.

... ‘choice and control’ ... was and is the phrase used by the disabled people’s movement to define independent living.⁶⁶

In all but three of the extracts, both were expressed as full, uncompromised ideas – that is, that disabled activists were not seeking *more* choice and control over their lives, but complete self-determination. Choice was not envisaged as a choice between options provided by external agencies, but a free choice of activity and lifestyle – or, essentially the *same* choices as non-disabled people experience. The idea of a ‘false’ choice was also referenced, in ways which held overtones of the idea of imposition and forced acceptance:

Some present this as their own choice: ‘I chose to go into residential care - it

⁶⁴ Bracking (n36) 13. The phrase was also used at the same conference in the paper by Maggie Davis, although this use was not connected with the phrase ‘independent living’. Davis, ‘Notes on the Historic’ (n60) 17 and 18.

⁶⁵ This was particularly true of the texts by Morris, in which the phrase was repeatedly used. When the documents were examined more widely, it was found that the phrase ‘choice and control’ appeared in all but three of the Anglo-British DPM dataset texts from 1992 onwards, in relation to various matters including support, personal assistance, and disabled people’s lives in general. As early as 1996, Ken Davis referred to choice and control as part of ‘the rhetoric of the disabled people’s movement’. Ken Davis, ‘Power’ (30) 4. The texts in which the phrase ‘choice and control’ did not appear after 1992 were Finkelstein 1998, ‘Re-thinking’ (n27); Vic Finkelstein, ‘The “Social Model of Disability” and the Disability Movement’ (2007) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-The-Social-Model-of-Disability-and-the-Disability-Movement.pdf>> accessed 2 January 2017 (a ‘dissenting’ text); and Inclusion London, ‘Manifesto’ (n53). The 2010 text by Jolly did not use the phrase ‘choice and control’, but did state that, ‘all disabled people including those that use or wish to use personal assistance want to exercise choice, control and self-determination over their own lives’. Debbie Jolly, ‘Personal Assistance and Independent Living’ (ENIL paper, 2010) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/jolly-Personal-Assistance-and-Independent-Living1.pdf>> accessed 10 November 2016, 5.

⁶⁶ Jenny Morris, *Rethinking* (n33) 5. See also: ‘Independent Living was started with the premise that it was to enable disabled people to have more control and choice over their lives. These are its two fundamental principles....’ Evans, ‘Understanding Our Past’ (n61), 1.

is just that it was the only choice there was'.⁶⁷

Personal agency was strongly connected to equality. This was expressed in two ways – as disabled people having the same level of self-determination as others; and as equality (and other outcomes) emerging from the existence of free self-determination.

In the independent living movement we reject these definitions that limit and control us. ... Society disables us by taking away our right to take decisions on our own behalf, and therefore the equality we are demanding is rooted in the concept of control; it stems from our desire to be individuals who can choose for themselves.⁶⁸

From the earliest stages, choice and control were also connected to rights:

Society disables us by taking away our right to take decisions on our own behalf...⁶⁹

In a handful of extracts, appearing from an early stage (1990), choice, control and self-determination were set against functional ability. These extracts explicitly connected agency with self-determination and disconnected it from functional capacity or self-reliance.

'What is important is that disabled people have the right to choose. Independent living is about choice and control, it is not about doing everything by yourself. Nobody - whether they have an impairment or not - can do everything themselves.'⁷⁰

⁶⁷ Jenny Morris, 'Independent Living and Community Care' (n27) 436, citing H Brown and C Croft-White with C Wilson and J Stein, *Taking the Initiative: Supporting the Sexual Rights of Disabled People* (Pavilion Publishing 2000).

⁶⁸ Brisenden (n2) 177-178.

⁶⁹ Ibid 177.

⁷⁰ Bracking (n36) 13. See also: 'The Independent Living Movement has tried to break the relationship between having choice and control in your life, and being able to physically do things for yourself.' Morris, 'The Meaning of Independent Living' (n32) 11.

There was also consideration of the exertion of choice and control by people with cognitive or communication impairments. Certain texts indicated that it was necessary to adapt the concept of independent living to enable the inclusion of different groups, and that this would impact on the understanding of choice and control.⁷¹

... concepts like choice, control ... – both in the way they have been conceptualised and applied in practice – have not fully embraced the needs and experiences of people with learning disabilities or mental health problems. Making choice and control possible for these groups would mean that the concept of independent living needs to be broad enough to include different ideas about things like how we define capacity for decision making
....⁷²

One of the core elements of the fragments of choice and control was that these ideas related to *self*-determination – that is, to the matter of the individual. Personal agency expressed the idea of each individual to live the life of his or her choice, under his or her own control. In some early extracts, the notion of the individual was emphasised:

We are individuals. Independent living gives expression to the uniqueness we have as individuals. ... It is recreating our own service day in and day out in the way that we want and in the way that we know best. ... It is a way of life that grows as you grow and develops as you develop.⁷³

In other extracts the idea of individual choice and control was latent, rather than explicit:

Just as everybody else, we need to be in charge of our lives, think and speak

⁷¹ Particularly Morris, 'The Meaning of Independent Living' (n32); Morris, 'Independent Living and Community Care' (n27); and Zarb, 'The Road to Inclusion' (n27).

⁷² Zarb, 'The Road to Inclusion' (n27) 201.

⁷³ Evans, 'The Role of CILs' (n60) 63. See also: '...the equality we are demanding is rooted in the concept of control; it stems from our desire to be individuals who can choose for themselves'. Brisenden (n2) 177.

for ourselves.⁷⁴

The fragments comprising personal agency were not wholly individualistic in their outlook – the extracts expressed a strong sense of a collective identity and solidarity, particularly through references to ‘we’, ‘us’, ‘our lives’, or ‘our desire’. The extract which perhaps conveyed the individual element of personal agency most strongly also expressed a powerful sense of community identity:

... the wealth of ingenuity and imagination of our fellow human beings can flourish as each person designs for him or herself independent living", as he or she works out his or her personal aspirations within the context of the real world, which, in exchange for this privilege it affords all citizens, demands the exercise of responsibility and citizenship. True equal opportunity, enabling the exercise of personal attributes in furtherance of personal responsibility and collective dependence.⁷⁵

4.1.1. Personal agency: Discussion

Nelson argues that two conditions have to be present for a person to act with free moral agency: control over one’s own actions (the ability to regulate one’s will reflectively) and ‘normative competence’. The latter involves three capacities: the ability to understand moral norms and act in accordance with them, the ability of others to recognise that one is morally competent, and the ability to see oneself as morally competent. If others or the self are unable to recognise moral competence, free agency is inhibited.⁷⁶

The master narratives identified by activists of deficit and incapacity, passivity,

⁷⁴ Oliver, quoting Ratzka (original source not provided). Mike Oliver, ‘Where Will Older People Be? Independent Living versus Residential Care’ (Conference: The Care and Management of Older People with Complex Needs, London, June 2001)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Oliver-where-will-older-people-be.pdf>> accessed 21 September 2017, pages unnumbered.

⁷⁵ HCIL, ‘HCIL Papers’ (n38).

⁷⁶ Nelson (n1) 22-28.

helplessness, vulnerability and sub-humanity fashioned disabled people as individuals without any ordinary capacity to self-determine and lacking such moral agency. They enabled both the absence of others' recognition of one's moral competence and the removal of disabled people's ability to see themselves as morally competent. This in turn enabled the development of policies and practices that reduced or denied opportunities for autonomy, causing both deprivation of opportunity and the infiltrated self. The narrative of personal agency within the dataset texts disputed this position directly, placing choice and control as central, definitional elements of the independent living counter-narrative. Indeed, the form of personal agency constructed within the documents went beyond Nelson's, which implicitly excludes individuals with certain psychological or cognitive conditions. In the Anglo-British DPM dataset, personal agency was specifically divorced from functional ability, and actually or potentially available to *all* people, regardless of the level of impairment, explicitly including cognitive impairment. In positioning particularly control at the heart of the independent living counter-narrative, the dataset texts constructed the lack of self-determination over their actions as an externally imposed difficulty, not as a 'deficit' or the failure of will or competence. The texts also *demonstrated* the ability of disabled people to think and to theorise. As a counter-narrative, they therefore operated on two levels; as a demand for, and an expression of, personal agency.⁷⁷

The distinction between choice and control, as the two central elements of the narrative of personal agency, was not explored at length in the texts. In effect, control performed the function of shifting authority from the public sector and professionals to disabled people; and choice the function of creating the possibility for non-restricted options within one's own life. The greater emphasis on control was partly accounted for by the experiences of early activists and the fact that control was implicitly considered to enable or to operationalise choice – that is, that an individual with control over his or her support and life exercises choice by default. Of the two ideas, choice is also the easier to weaken. While both control and choice can

⁷⁷ Shakespeare suggests that one of the purposes of collective action and the self-organisation of excluded groups is to challenge dominant discourses that oppress and diminish status, with a particular focus on the regaining of control. Tom Shakespeare, 'Disabled People's Self-Organisation: A New Social Movement?' (1993) 8(3) *Disability, Handicap & Society*, 249-264, 262, citing A Melucci, *Nomads of the Present* (Radius 1989).

be diminished through qualification (individuals having *more* rather than *total* choice or control), choice also has the potential to be reduced to a selection between available options. Where the level of choice is not indicated it may or may not refer to unconstrained choice – an ambiguity to which control is less susceptible. The matter of control also requires a level of distancing between state agencies and the individual – explicitly characterised in certain extracts in the DPM texts as the shift of power from one to the other. *Full* control over support impliedly requires the movement of resources and responsibility. Full choice, in contrast, does not demand such movement, although it may be desirable. Control therefore *necessitates* a separation between state agencies and the person that is not inevitable for choice to be exercised.

Nelson's conceptualisation of moral agency related to the agency of the self. Similarly, the narrative of personal agency in independent living expressed a matter of *individual* integrity and empowerment. This clearly emerged as resistance to the denial of self-determination the authors had personally experienced, with personal wishes, aspirations and preferences both experienced and emphasised as the antidote to what UPIAS had described as 'batch' living.⁷⁸ The fact that the intrinsically personal matters of choice and control were described as the essential, even *definitional*, principles of independent living; and the fact that these were expressed in uncompromised terms, placed individualism at the heart of the counter-narrative. This is not to say that choice and control are *necessarily* or *inherently* individualistic. Both can be, and frequently are, operated on a collective basis. What was necessary for disabled people, however, and particularly the pioneers of independent living, was the ability to decide for oneself and have a life of one's own.

The strong narrative of personal agency created both individual and political opportunities. For disabled people accustomed to master narratives of passivity and personal tragedy, and with roles of recipient and dependent socially formed for them, the idea of self-determination represented new opportunities for self-image and a means to correct the damage of the infiltrated self. In connecting this discourse of

⁷⁸ UPIAS, 'Policy Statement' (n2) para 7. The term 'batch living' was coined by Goffman in his work on institutions. Erving Goffman, *Asylums: Essays on the Social Situations of Mental Patients and Other Inmates* (Harmondsworth 1961).

self-determination to equality and rights, disabled activists framed personal agency as a matter of social justice, creating a narrative that held political implications connected to citizenship and discrimination.

4.2 Social agency: an active fulfilling life in the community

This cluster contained narrative fragments that were thematically connected to the matters of inclusion and activity. They included a life in everyday communities, inclusion, participation and the need for a meaningful, fulfilled life. Employment and education were also present. Community life in this context referred to the matter of living in an ordinary local town, village or city, and was often connected to the idea of having one's own home.⁷⁹ As with personal agency, the narrative of social agency built on ideas that had been articulated prior to the emergence of the idea of independent living in the UK. The original impetus and campaigning focus of UPIAS – as its name suggests – had primarily been the matter of the separation and segregation of disabled people from society, and the damage inflicted on disabled individuals – both in terms of their life opportunities and their internally and externally constructed identities – as a result.⁸⁰

The fragments of an active and meaningful life, inclusion and participation were particularly closely intertwined, appearing in the same extracts.⁸¹ The fragment of community living was situated alongside these ideas less frequently in the extracts, but was almost invariably implicitly or explicitly positioned as an underlying and absolute condition for independent living. Its centrality was reinforced by references to the origins of the movement:

Independent Living was born in the UK as an alternative to institutions when a

⁷⁹ The code for community living included references to non-institutional living. There were 44 references in the extracts, across 14 texts.

⁸⁰ UPIAS, 'Policy Statement' (n2).

⁸¹ There were 43 references to having a meaningful life in the extracts, across 18 texts. Inclusion and participation were particularly closely connected, reflecting the close link between these two ideas. In the extracts, there were 37 references to inclusion across 16 texts and 28 references to participation across 14 texts.

group of us moved out of Le Court Cheshire Home in the early 1980s.⁸²

Independent living was consistently positioned as the direct opposite of institutional living:

Most disabled people, especially those with high support needs, are fearful of being forced into 'residential care' ... which is viewed as the antithesis of independent living.⁸³

When institutionalisation was discussed, a strong sense of imposition was conveyed. In language that echoed that of UPIAS, which described institutions as 'the ultimate human scrap-heaps',⁸⁴ the extracts connected institutions with 'ghettoes',⁸⁵ 'imprisonment',⁸⁶ 'incarceration',⁸⁷ and with the idea of people being forced into particular living arrangements, dominated and overwhelmed, with their humanity denied.

...it is still seen as acceptable for disabled people to be living in institutions against their wishes, to be denied access to basic support to enable them to enjoy a family or social life, and to be guaranteed no more than the bare

⁸² Evans, 'Understanding Our Past' (n61) 2. See also: 'Many Disabled people's care and support has been cut down to a very basic clean and feed model, as a result full inclusion and participation in the community has become impossible. Independent living as a right and as a way of life, is being systematically dismantled.' Inclusion London, 'Evidence of Breaches of Disabled People's Rights under the UN Convention on the Rights of Persons with Disabilities' (2015) <<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/equality-and-human-rights/evidence-of-breaches-of-disabled-peoples-rights-under-the-un-convention-on-the-rights-of-persons-with-disabilities/>> accessed 2 January 2017, 8.

⁸³ Colin Barnes, 'Independent Futures: Policies, Practices and the Illusion of Inclusion' (presentation to ENIL, November 2006) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/Barnes-valencia-presentation-Colin.pdf>> accessed 18 November 2016, 21, citing Breakthrough UK, 'A Response to the Prime Minister's Strategy Unit Report Improving the Life Chances of Disabled People' (2005). See also: '... people for whom independent living is considered to be too expensive are faced with a stark choice between struggling to maintain their independence in the community, or entering institutional care'. Zarb, 'Road to Inclusion' (n27) 194.

⁸⁴ UPIAS, 'Policy Statement', para 6. The full quote reads: 'The union of the Physically Impaired believes that the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrap-heaps of this society. Thousands of people, whose only crime is being physically impaired, are sentenced to these prisons for life -which may these days be a long one. For the vast majority there is still no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself'.

⁸⁵ Brisenden (n2) 177.

⁸⁶ Evans, 'Understanding Our Past' (n61) 3.

⁸⁷ Morris, 'The Meaning of Independent Living' (n32) 1.

minimum services necessary for day to day survival.⁸⁸

Like choice and control and community living, inclusion and participation were presented as central elements of independent living, although they did not carry the same definitional sense. The need for full, rather than partial, inclusion and participation was emphasised, with phrases such as 'full inclusion' or 'participate fully' frequently deployed. Rights were also referenced:

Independent living is more than just living outside an institution it is about rights - equal rights and opportunities for all disabled people. It is about the complete integration and inclusion of disabled people into all aspects of society.⁸⁹

Together with the idea of having an active, meaningful life, the ideas of inclusion and participation were used to create a sense of 'ordinariness' for disabled people. While this word was not used,⁹⁰ these fragments expressed involvement in the activities that are (generally) accepted by non-disabled people as being typical elements of daily life including, in particular, employment and education.⁹¹ As with self-determination, they were strongly linked to a discourse of equality, with this theme

⁸⁸ Zarb, 'The Road to Inclusion' (n27) 204.

⁸⁹ Bracking (n36) 13.

⁹⁰ This word was used in one extract only across these themes, in relation to carers desiring 'an ordinary family relationship' with the disabled individuals they support. Jane Campbell, 'Fighting for a Slice, or for a Bigger Cake?' (The 6th Annual Disability Lecture, St John's College, University of Cambridge, April 2008) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Campbell-Fighting-for-a-slice-of-the-cake-FINAL-FINAL-29-04-08.pdf>> accessed 16 November 2016. 13. In the texts more widely, Mason also referred to: 'ordinary lives at work rest and play'. Philip Mason, 'Back to Basics' (opening presentation at HCIL conference: Facing Our Future: Experts' Seminar on Independent Living and Direct Payments, July 1998) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-facing-our-future.pdf>> accessed 18 November 2016, pages unnumbered. While not common in the dataset texts or other texts from the disabled people's movement, the idea of 'ordinariness' occurs in relation to people with learning disabilities, and particularly the closure of longstay hospitals for this group. The Kings Fund document, 'An Ordinary Life: Comprehensive Locally-Based Residential Services for Mentally Handicapped People' (Kings Fund Centre 1980) started what became known as the 'Ordinary Life Movement'. The document cites David Thomas and Honor Woods, *Working with People with Learning Difficulties: Theory and Practice* (Jessica Kingsley Publishers 2003) 67-68.

⁹¹ For example, 'Independent living is about access; access to schools, jobs, transport, houses, public buildings and leisure etc.- all the things that non-disabled people take for granted -and about disabled people having control of the services they need.' Bracking (n36) 14. And: 'Opportunities for economic participation are an essential part of independent living. However there are many examples of people being prevented from participation in training or employment.' Zarb, 'The Road to Inclusion' (n27) 196.

closely woven in with these narrative fragments. Many of these extracts also connected social agency to the fragments of choice and control that were central to the notion of personal agency. Overall, they constructed disabled people as competent social actors with everyday individual lives within the wider social context.

Independent Living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own.⁹²

This extract emphasised the matter of access and the connection between independent living and the social model, which was an underlying theme in the extracts, particularly in relation to social agency. Access underwrites the notion of inclusion and participation, and was implicit in this discussion as a requirement of using public transport, going to a local school or having a job. Some of the extracts made this connection explicit:

Independent living is about access; access to schools, jobs, transport, houses, public buildings and leisure etc. -all the things that non-disabled people take for granted -and about disabled people having control of the services they need.⁹³

The extracts that contained the fragments of inclusion, participation and a full and active life were rich with the ideas of quality of life and humanity. References were

⁹² Oliver, 'Older People' (n74) pages unnumbered, quoting Ratzka (original source not provided). See also: 'Basically, independent living means disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community'. Zarb, 'The Road to Inclusion' (n27) 192. This quote references the DRC definition of independent living cited in Chapter 2, section 4.

⁹³ Bracking (n36) 14.

made to sexuality,⁹⁴ the need for personal relationships,⁹⁵ individual personality,⁹⁶ and personal development.⁹⁷ Particularly when they were combined with the fragments that made up personal agency, these ideas developed disabled individuals as unique people with roles and responsibilities and a vibrant connection with everyday community life on the same basis as people without impairments.

4.2 1. Social agency: Discussion

The strong relationship between counter-narratives and the experience of exclusion or marginalisation is explored in Chapter 4. Nelson and multiple other authors theorise counter-narratives as the product of marginalised or excluded groups, to the extent that marginalisation is deemed to be effectively a condition for counter-narrative development. The narrative of social agency created within independent living was in a sense a 'pure' counter-narrative, in that it represented resistance to marginalisation at a fundamental, oppositional level, tackling the subject of absolute exclusion. For these authors, the question was not a matter of, for example, how they were marginalised or poorly viewed within an educational establishment or workplace, but their full, physical, removal from society. This 'pure' counter-narrative built on the protest against segregation and removal that was present from the earliest days of the disabled people's movement.

The focus on community life and inclusion also extended well beyond a rejection of exclusion and marginalisation. Nelson argues that master narratives create identities in which individuals or groups are crafted as 'morally sub- or abnormal' in such a way that they can be prevented from 'occupying roles or entering into relationships that

⁹⁴ Dennis Killin, 'Independent Living, Personal Assistance, Disabled Lesbians and Disabled Gay Men' (presentation at BCODP seminar 'Making Our Own Choices', 1992) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019.

⁹⁵ Ibid; Peter Beresford, *What Future for Care?* (Joseph Rowntree Foundation 2008); Campbell, 'Fighting for a Slice' (n90) 2008.

⁹⁶ 'Independent living ... is about people's lives and the quality of their lives, and who we are as people. That is the important thing.' Evans, 'The Role of CILs' (n60) 63.

⁹⁷ 'Disabled people are no different to anybody else. We develop as people socially, economically, politically and philosophically.' Ibid, 63.

are identity-constituting'.⁹⁸ The aim of the resisting narrative is therefore typically not simply the creation of an identity that is worthy of respect, but one which can assume a 'rightful' non-marginalised place in society. The identification of master narratives of abnormality and sub-humanity correlate precisely with this assessment. The social agency created in these texts performed a crucial element of narrative repair through resisting this 'othered' identity in which disabled people had been constructed as defective, inadequate, flawed, and inferior. The texts set about neutralising and subverting these narratives by creating social roles for disabled people that rested on their existence as *people*, with typical and varied social ambitions. In emphasising social roles, citizenship and family and community connections ('brothers and sisters, neighbours and friends') as well as equality and aspects of the human experience such as sexuality, exclusion and segregation were established as *unnatural* states rather than expected or acceptable conditions. Inclusion and participation were not ends in themselves, but tightly bound up with expressions of humanity.

The essential purpose of social agency was to construct disabled people – both individually and as a sector of the population – as an integral and integrated part of the wider community. Integration, inclusion and participation are communitarian ideas, and the language of equality and citizenship demonstrated a collective identity not just among disabled people, but between disabled people and others. In addition to demonstrating a rightful place in society, it resonated with the communitarian ideas of the disabled people's movement and the social model. However, it also retained a profound notion of the self. The connection of social agency to personal agency indicated that the engagement of individuals in everyday and community activities should be on their own terms to enable the lives of the individual's own choice. While the narrative of personal agency might be considered to reflect the individual's internal identity; and that of social agency their community identity, the matter of *individual* integrity was central to both narratives.

Overall, the narrative of social agency created a wholly new form of disabled identity, based on *sameness* rather than distinction between disabled and non-disabled

⁹⁸ Nelson (n1) 20.

people and rejecting the master narratives of deficit and otherness in their entirety. In individual terms, the narrative gave permission and scope – both to the authors and to other disabled people – to think of themselves not as social rejects or as somehow ‘defective’, but as workers, partners, parents, participants. It demanded an end to deprivation of opportunity and demonstrated a means to counter the infiltrated self. Social agency, particularly when connected to the narrative of self-determination and reinforced with its strongly articulated thread of equality and references to rights, created a discourse of entitlement, citizenship and human value which, like those of personal agency, held particular implicit and explicit demands.

4.3. Equality and rights

The narratives of both personal and social agency were infused with the language of equality and rights. These fragments are considered separately here for two reasons: firstly because of the connection of these ideas both to each other and to further narratives of citizenship and entitlement;⁹⁹ and secondly because these ideas had a function in the texts that extended beyond their role as fragments of a counter-narrative, accomplishing more than an act of narrative repair.

As noted in the relevant sections above, in the extracts, equality was placed alongside and woven together with the component fragments of personal and social agency. Brisenden suggested that demands for equality arose directly from the experience of segregation:

the medical definition or model has to a great extent contributed to placing us outside society, in special institutions and ghettos. We desire a place in society, participating as equal members with something to say and a life to

⁹⁹ Rights and equality are linked. The purpose of universal human rights is to set out a basis for the common humanity of all people and establish their equal legal status. The first sentence of the preamble of the Universal Declaration of Human Rights recognises ‘the equal and inalienable rights of all members of the human family’ and Article 1 states: ‘All human beings are born free and equal in dignity and rights’. United Nations, ‘Universal Declaration of Human Rights’ (proclaimed 10 December 1948) <<http://www.un.org/en/universal-declaration-human-rights/>> accessed 30 May 2018.

lead; we are demanding the right to take the same risks and seek the same rewards.¹⁰⁰

Equality was essentially expressed as an aim of disabled people. The majority of the extracts in which it was directly connected to independent living articulated variations on this theme, with authors expressing a desire (or a demand) for equal opportunity,¹⁰¹ equal citizenship,¹⁰² equal social access,¹⁰³ equal worth,¹⁰⁴ and equal rights.¹⁰⁵ From the early days of independent living, disabled activists therefore developed out of their lived, segregated experiences a comprehensive notion of equality, forming the basis for an activist narrative of citizenship.¹⁰⁶

Equality was also expressed as a pre-existing state – that is, that disabled people *were* the same as others, sharing common human interests, ambitions and experiences. This was particularly found in early documents.

Every day is different even if you have what is supposedly a routine lifestyle. That is the fascination of independent living. Disabled people are no different to anybody else. We develop as people socially, economically, politically and philosophically.¹⁰⁷

Rights was related less emphatically than equality to the ideas of personal and social agency, with fewer references in extracts that constructed these narratives. However, rights also stood apart from these narratives and were very highly

¹⁰⁰ Brisenden (n2) 177.

¹⁰¹ 'The outcome of this was the Strasbourg Resolutions which asserted our desire to be given the means to enable equal opportunity at work, rest and play through funds to purchase personal assistance.' Mason, 'Back to Basics' (n90) pages unnumbered.

¹⁰² 'We want equal opportunities. We want equal citizenship. These are the issues that drive the independent living movement.' Evans, 'The Role of CILs' (n60) 63.

¹⁰³ 'There's not much point in having control over the help you need if you can't use public transport, get a job, get the education you need, get access to goods and services on the same terms as everyone else.' Morris, 'The Meaning of Independent Living' (n32) 4-5.

¹⁰⁴ 'A crucial issue for advocates of a social model of disability and independent living is the importance of policies of equal worth for disabled and non-disabled people.' Barnes, 'Independent Futures' (n83) 16.

¹⁰⁵ 'Independent living is more than just living outside an institution it is about rights -equal rights and opportunities for all disabled people. It is about the complete integration and inclusion of disabled people into all aspects of society.' Bracking (n36) 13.

¹⁰⁶ Citizenship itself was explicitly connected with independent living 16 times in the texts.

¹⁰⁷ John Evans, 'The Role of CILs' (n60) 63.

referenced. Rights, and the associated idea of entitlement,¹⁰⁸ were connected to independent living in 111 extracts across 17 documents from 1986 to 2017, including references to Article 19 of the CRPD. The narrative fragment of rights therefore went well beyond the discussion of personal and social agency. In the extracts, rights was a core theme of its own, attached to independent living more strongly than almost any other idea.¹⁰⁹

In the extracts rights appeared not only as a narrative that emerged from the personal experiences of disabled people; but as a separate matter intentionally added to the idea of independent living by disabled activists. This indicated a theorising of independent living and a connection to distinct political and legal ideas. Independent living itself was uncompromisingly constructed as a human right from a very early stage, with emphasis placed on the fact that this connection was specifically made by the disabled people's movement:

It is important to remember that the idea of independent living for disabled people as a right has evolved from within the disability rights movement – and not from within able-bodied society.¹¹⁰

The relationship between independent living and rights was multi-faceted. Independent living was constructed as *both* the means to access human rights and the expression of them. This very close connection was articulated in particular by Morris, Evans and Zarb.

At the same time, the broader disability movement has made real progress on the issue of civil rights – which of course underpins the whole concept of independent living.¹¹¹

Independent living itself is a means to an end: it is a way of people accessing

¹⁰⁸ These were coded together in the coding structure.

¹⁰⁹ Only the code 'threats to independent living' was more highly referenced, with 131 extracts relating to this theme.

¹¹⁰ Bracking (n36) 11. See also, 'We see [independent living] as a right that has to be restored to us rather than a freely given gift'. Brisenden (n2) 178. Across the texts, there were 64 references in which independent living itself was framed as a right.

¹¹¹ Morris, 'The Meaning of Independent Living' (n32) 4.

their human and civil rights.¹¹²

There was a large increase in the number of extracts in which independent living was connected to rights in documents from 2001 onwards, and particularly from 2004.¹¹³ This was partly because of the inclusion in the dataset of the Zarb and Jolly documents, which considered respectively the possibility of creating a legal right to independent living and Article 19 of the UNCRPD. However, overall it appeared that the disabled people's movement was gaining confidence with the idea of framing independent living in rights terms, particularly from the time of the development of the UNCRPD.¹¹⁴

The focus on rights and equality extended well beyond the extracts related to independent living, and was a pivotal focus in the texts more generally. In 2001, Oliver listed the shift 'from charity to rights' alongside independent living and the social model as the 'big ideas' devised by the disabled people's movement to reject the positioning of disabled people as a group 'in need of care and management'.¹¹⁵ In doing so, he effectively framed rights as a third activist counter-narrative for the movement,¹¹⁶ albeit one that existed separately and prior to matters of disability.

The examination of the texts beyond the extracts related to independent living also uncovered concerns connected to the idea of rights, including among authors who were committed to rights-based approaches. Oliver suggested that anti-

¹¹² Morris, 'Independent Living and Community Care' (n27) 428. See also Evans, 'Without Independent Living we do not have our Human Rights and without Human Rights we do not have Independent Living'. Evans, 'Understanding Our Past' (n61) 9.

¹¹³ Of the 64 extracts in which independent living itself was constructed as a right (see n110), 56 occurred from 2004.

¹¹⁴ The UNCRPD was adopted by the UN in 2006 and ratified by the UK in 2009. Negotiations on the content of the UNCRPD began in 2002. Campaigns by the disabled people's movement to have a right to independent living enshrined in domestic legislation also took place at around the time of the UNCRPD negotiations (see Chapter 2, section 4, where it is noted that four bills to this effect were introduced to the UK parliament between 2005 and 2009).

¹¹⁵ Oliver, 'Older People' (n74) pages unnumbered. In a dissenting text, Finkelstein expressed concern about these, suggesting that independent living and rights should be seen as core elements of the social model, rather than separate ideas. Finkelstein referred to Oliver's three 'big ideas' as the 'troika'. Finkelstein, 'Social Model' (n65) 6.

¹¹⁶ This idea exists well beyond Oliver. It is noted in Chapter 2, section 4 that the UNCRPD does not simply establish a series of socio-economic rights for disabled people, but shifts the underlying narrative that has surrounded this group from one of 'charity' or 'welfare' to one of rights and entitlement (see also discussion in Section 5 of this chapter).

discrimination legislation was a valuable tool of the state in containing the demands of excluded social groups and enabling the continuance of the status quo.¹¹⁷ In a dissenting text, Finkelstein argued that rights were essentially compensatory, depending on the identification of certain groups as in particular need, and thus reinforced narratives of individual rather than social deficit.¹¹⁸ Zarb also expressed concern that the individual aspect of rights-based solutions was incompatible with the communitarian approach of the social model, which called for structural change to remove barriers for all. In particular, Zarb cited arguments by Oliver and Finkelstein that a focus on rights could potentially undermine the 'collective emancipation of disabled people'.¹¹⁹

4.3.1 Equality and rights: Discussion

The fragments of equality and rights held particular implications in the independent living counter-narrative. These concepts, particularly rights, are highly activist and have legal connotations. In placing equality so centrally within the counter-narrative, the authors developed independent living as a matter of social justice, opening up opportunities to connect it with the legal idea of discrimination. In framing independent living as a right, the disabled people's movement constructed it as a quasi-legal entity, setting it out as a profoundly politicised demand from the outset. The denial of rights – particularly one's fundamental human rights – indicates a form of oppression against which there is legitimate moral and *legal* complaint. In connecting independent living so closely with human rights, disabled activists claimed the particular social and legal status of rights-holders, framing all disabled

¹¹⁷ Oliver, 'Social Policy' (n4) 11.

¹¹⁸ Finkelstein, 'Social Model' (n65). In a non-dataset text, later cited by Zarb, Finkelstein argued that the disabled people's movement had been dangerously drawn in to a wider and hostile agenda. He stated: 'Indeed this illusion about what are in practice 'compensatory' civil rights being a big idea is so enchanting that even the disability movement has been captivated (much to the delight of politicians with abilities) into believing that civil rights can provide a platform for announcing our commitment to emancipation.'

¹¹⁹ Zarb, 'Road to Inclusion' (n27) 203-204, citing Vic Finkelstein, 'A Personal Journey into Disability Politics' (presentation, Centre for Disability Studies, University of Leeds, 7th February 2001) and Michael Oliver, 'Disabled People and the Inclusive Society? Or the Times They Really Are Changing' in S Riddell (ed), *Disability and Civil Rights in the New Millennium* (Strathclyde Centre for Disability Research 2001).

people as human beings on an equal social and legal footing with their non-disabled peers – a matter later legally articulated in the UNCRPD. The fragments of equality and rights therefore performed two interconnected functions. By constructing disabled people as equal citizens and rights-bearers, these fragments accomplished *both* the act of narrative repair, raising the social status of disabled people and countering master narratives of ‘care’, ‘welfare’ and ‘charity’, *and* the elevation of this new identity to a different political and legal level. The discourse of equality and rights created the possibility of placing independent living onto a formal legal footing and the potential for future individual or collective litigation. Within independent living therefore, the ideas of equality and rights acted not simply as fragments of a repudiating counter-narrative, but as a political strategy.

The development of the concepts of equality and rights, and the increase in such references in later documents in the dataset, did not occur in a vacuum. The Disability Discrimination Act 1995 gave a new legal and social voice to disabled people, creating and confirming an identity for disabled people as entitled citizens and rights-holders. Over a similar period, there was increasing ‘rights-talk’ in the wider UK political landscape.¹²⁰ The passage and implementation of Human Rights Act 1998 ‘normalised’ the discussion of human rights and created a new legal and political lever for disabled people that was based not on their *disabled* identity, but on their identity as UK citizens. In international terms, the adoption of the UNCRPD provided a radical new legal instrument which both established certain rights for disabled people and altered their legal status. In connecting independent living to equality, discrimination and human rights, disabled activists in the UK deployed ideas that were rapidly gaining political traction and which were connected with the broader development of a new narrative and legal identity for disabled people.

The use of a narrative of rights, however, meant that the movement was inserting the idea of independent living into a social and legal frame that had the power to cause damage both to its radical potential and to collectivist principles that the movement

¹²⁰ Debate on reform of the UK constitution and demands for an entrenched UK Bill of Rights gathered pace in the UK with the foundation in 1988 of Charter 88 – a highly visible political, academic and popular movement that called for an established bill of civil and political rights, electoral and parliamentary reform and freedom of information. See, Stephen Howe, ‘Some Intellectual Origins of Charter 88’ (2009) 62(4) Parliamentary Affairs 552.

prioritised. The discussion of rights as a vehicle for the survival and perpetuation of dominant narratives and the status quo extends well beyond the context of disability.¹²¹ Similarly, the potential of rights – as an *individualistic* response – to damage *collectivist* approaches, including those of the welfare state, has also been widely articulated.¹²² The narrative fragment of ‘rights’ was therefore complex, containing multiple and potentially conflicting ideas of sameness and ‘otherness’ between disabled and non-disabled people.

4.4. Enablers of independent living: Personal assistance and direct payments

Several enabling structures were connected to independent living within the texts. Two of these – personal assistance and direct payments – stood out as particularly important. Direct payments are sums of money provided by local authorities to disabled people to enable them to purchase their own assistance.¹²³ Since the early

¹²¹ See, for example, Golder’s examination of Kennedy’s work on human rights. Ben Golder, ‘Beyond Redemption? Problematising the Critique of Human Rights in Contemporary International Legal Thought’ (2014) 2(1) *London Review of International Law*, 77. See also, Marius Pieterse, ‘Eating Socioeconomic Rights: The Usefulness of Rights Talk in Alleviating Social Hardship Revisited’ (2007) 29(3) *Human Rights Quarterly* 796; and Helen Carr and Caroline Hunter, ‘Rights are attractive to a state wishing to demonstrate compassion without increasing its direct responsibility for the provision of care’. Helen Carr and Caroline Hunter, ‘Are Judicial Approaches to Adult Social Care at a Dead-End?’ (2012) 21(1) *Social & Legal Studies* 73, 79. In relation to matters of equality and anti-discrimination legislation (in relation to the position of women), see Martha Fineman, ‘Evolving Images of Gender and Equality: A Feminist Journey’ (2009) 43 *New England Law Review* 101.

¹²² TH Marshall wrote on the matter of social, as opposed to individual rights. TH Marshall, *Citizenship and Social Class* (Cambridge University Press 1950); Bryan S Turner (2009) T.H. Marshall, *Social Rights and English National Identity* (2009) 13(1) *Citizenship Studies* 65. Similarly, Aneurin Bevan argued that individual rights were essentially achieved through collective state support and action. See Claire Beckett and Francis Beckett, *Bevan* (Haus 2004). Wilmot-Smith notes that ‘Beveridge, Bevan and Morrison were particularly resistant to legal oversight of the social welfare system’ owing to their belief that political institutions were the means to secure welfare and social justice. In this context, Wilmot-Smith notes that injustice ‘was not one of Beveridge’s “giants”’ – the destruction of the ‘giants’ of squalor, ignorance, want, idleness and disease were seen as the means to secure justice for all. Frederick Wilmot-Smith, ‘Necessity or Ideology?’ (2014) 36(21) *London Review of Books* 15. Historically, therefore, discourses of rights and welfare in the UK context have not necessarily been viewed as mutually supporting ideas.

¹²³ See Chapter 2, section 4. In both England and Wales direct payments are provided to an individual once their needs have been assessed and an eligibility decision reached. The individual must consent to the use of direct payments and certain requirements must be met. An assessment is conducted and eligibility criteria applied as for any other form of social care provision. In England, direct payments are now primarily governed by the Care Act 2014. In Wales they are governed by the

days of the movement they have typically been used by disabled people to employ ‘personal assistants’ – individuals who carry out a variety of tasks as required by the disabled person, and under the disabled person’s supervision. As well as being more frequently connected to independent living than other enablers,¹²⁴ both direct payments and personal assistance were expressed as a fundamental part of the counter-narrative. In this section they are discussed first, with discussion of other enablers following.

Personal assistance and direct payments were referenced back to the experiences and activities of the early activists who pioneered these methods of support. Texts by Evans and Morris in particular, indicated that direct payments, in the form that they are known today, were direct descendants of the early payments made to a handful of individuals in Hampshire,¹²⁵ and the result of the subsequent activism of the disabled people’s movement.¹²⁶ Like other elements of independent living, therefore, personal assistance and direct payments grew directly out of the lived resistance of disabled people.

Both personal assistance and direct payments were seen (separately and together) as critical for the existence or achievement of independent living.

The idea of personal assistance in the development of independent living is crucial. I think it is fundamental to independent living.¹²⁷

Social Services and Well-being (Wales) Act 2014. Successive Westminster governments have promoted direct payments as the preferred method of social care support, as part of the personalisation initiative, since they were first placed on a sound legal footing in 1996.

¹²⁴ There were 67 references to personal assistance in the extracts and 36 references to direct payments. This was partially accounted for by the inclusion of one document with a particular focus on personal assistance and one with a particular focus on direct payments.

¹²⁵ Across the extracts as a whole, two of the references to personal assistance, three to direct payments, and three which incorporated both these ideas were connected back to the early pioneers, particularly those from Le Court. For example, ‘As long as people remained dependent on services over which they had no control they still could not choose when they got up and when they went to bed, and so on. So the growing disabled people’s movement and the increasing number of Centres for Independent Living put pressure on local authorities to provide more empowering services and, in particular, to give disabled people the cash so that they could purchase the help they needed themselves.’ Morris, ‘The Meaning of Independent Living’ (n32) 3.

¹²⁶ In particular, Evans, ‘Understanding Our Past’ (n61).

¹²⁷ Evans, ‘The Role of CILs’ (n60) 60.

...disabled people's organisation have championed direct payment schemes as a prerequisite for independent living for more than two decades in the UK...¹²⁸

In both the extracts and the broader documents, direct payments and personal assistance essentially replaced the ideas of 'care' and 'services'. It is personal assistance, not 'social care support' that forms one of the 12 'pillars' of independent living, and its centrality is emphasised by the fact that it has been consistent through the development of those pillars.¹²⁹ In certain documents personal assistance was expressed as almost as synonymous with independent living.¹³⁰ Both mechanisms were seen as critical to achieving specific outcomes of independent living, including equality, and to enabling a life in the community. For example:

We, disabled people believe that the purpose of Direct Payments is to enable Independent Living. In other words it is to ensure that disabled people are able to live like everybody else, with the equality of opportunity.¹³¹

Personal assistance and direct payments were framed as essential to the personal and social agency of disabled people. Personal assistance, funded by direct payments, formed the means of connecting the individual's ability to *have and to know* one's own will to the ability to *act* upon it. These mechanisms provided the essential means of enabling personal agency and overcoming impairment:

¹²⁸ Barnes, 'Independent Futures' (n83) 14.

¹²⁹ See Chapter 2, section 4. It should be noted that in some recent articulations of the pillars, social care is combined with health care, although personal assistance remains extant. See Inclusion London, 'Disabled People's Manifesto: Reclaiming Our Futures' (2013) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/UK-Disabled-People-s-Manifesto-Reclaiming-Our-Futures.pdf>> accessed 2 January 2017.

¹³⁰ See in particular the presentations at the 1992 BCODP conference, BCODP, 'Making Our Own Choices' (1992) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019. For example: '...how can you exert a positive choice to have independent living and acquire personal assistance?' Nasa Begum (n57) 52. The full title of this conference is cited as: 'Making Our Own Choices: Independent Living, Personal Assistance And Disabled People'. See also Jolly (n65). For example, 'not everything is running as smoothly or completely within the independent living and personal assistance framework as we would like' (page 7).

¹³¹ Evans, 'Understanding Our Past' (n61) 1.

The particular issue ... is that of control over the Personal Assistants required to overcome individual physical and/or intellectual limitations.¹³²

Personal assistance and direct payments were also framed as the means of transferring control from services to the individual.

These are cash payment schemes paid directly to service users that enable them to buy support in the form of a 'care' attendant, or personal assistant (PA), rather than be dependent upon statutory or voluntary services that are generally controlled and run by someone else'.¹³³

Beyond the extracts, some texts impliedly excluded the use of direct payments and personal assistance by people with cognitive or communication impairments.

However, [the term 'independence'] can be applied to the most severely disabled person who lives in the community and organises all the help or 'care' they need as part of a freely chosen lifestyle.¹³⁴

There was some discussion of how this might be overcome. In 2004, Zarb argued that the development of an inclusive model of independent living entailed the risk of dilution of personal assistance and other 'originating principles', but emphasised that it was necessary to find a balance to enable and ensure inclusivity.¹³⁵ Other authors suggested broad solutions, although detail was limited.¹³⁶

¹³² HCIL, 'HCIL Papers' (n38) pages unnumbered. See also Morris, 'Giving people the purchasing power is ... the most effective way of turning someone from a 'dependent' into someone who decides who delivers the help they need, how and when'. Morris, 'The Meaning of Independent Living' (n32) 12-13.

¹³³ Colin Barnes, 'Independent Futures' (n83) 9. See also: 'A central element of 'independent living' is personal assistance and, in particular, having direct access to the cash which gives freedom to hire and fire assistants who carry out duties determined by and under the control of the disabled person him or herself'. Davis, 'Notes on the Historic' (n60) 15.

¹³⁴ Brisenden (n2) 178. See also, 'The important element is whether the disabled person has the right to say 'no', to hire and fire at will, and to control payments'. Bracking (n36) 13.

¹³⁵ Zarb, 'Road to Inclusion' (n27) 201-202. This is the same extract as considered in Section 4.1 above, in relation to how the ideas of choice and control might be extended to individuals with cognitive and communication impairments.

¹³⁶ Morris considered the imposition of a duty on local authorities to provide assistance with the use of direct payments. Morris, 'Independent Living and Community Care' (n27). Shakespeare also considered a number in a dissenting text. Shakespeare, *Help* (n35).

On occasion, and particularly in the earlier documents, direct payments were discussed in the language of purchasing or marketisation. This echoed references in some of the texts beyond the extracts that referred to disabled people as ‘consumers’ of support.¹³⁷ This idea was acknowledged to come from the independent living movement in the States,¹³⁸ although it also resonated in the UK¹³⁹ and internationally.¹⁴⁰

One recurring theme in the discussion of both direct payments and personal assistance was that of threat to their free and continued existence. Both resource¹⁴¹ and conceptual concerns were indicated. In relation to the latter, there was unease about the control of direct payments by state agencies,¹⁴² and potential dilution of the principles of choice and control if direct payments schemes were operated by non-DPOs or professionals.¹⁴³ Overall, there was a fear that the agency of disabled people might be restricted by a form of ‘takeover’ of the ideas, principles and models created by the disabled people’s movement. Evans expressed this in terms of ownership.

This again reminds us that such potential threats need to be countered by disabled people and their organisations to remain in control of Independent Living and Direct Payment services.... Our investment and ownership in Direct Payments have to be constantly strengthened.¹⁴⁴

¹³⁷ See in particular, HCIL, ‘HCIL Papers’ pages unnumbered. The language of disabled people as ‘consumers’ of services also occurred in Barnes, *Cabbage Syndrome* (n30) 129

¹³⁸ Ken Davis, ‘Notes on the Development of the Derbyshire Centre for Integrated Living (DCIL)’ (DCDP, December 1984) <<http://disability-studies.leeds.ac.uk/files/library/DavisK-earlydcil.pdf>> accessed 1 June 2015, para 5.2.

¹³⁹ The letter by Paul Hunt to The Guardian that initiated the development of UPIAS and is widely considered to be the origin of the UK disabled people’s movement more widely stated: ‘I am proposing the formation of a consumer group to put forward nationally the views of actual and potential residents of these successors to the workhouse’. Paul Hunt, ‘Letter to The Guardian’ *The Guardian* (London, 20 September 1972).

¹⁴⁰ European Network for Independent Living, ‘The Strasbourg Resolutions’ (1989) (*Independent Living Institute*, undated) <<https://www.independentliving.org/docs2/enilstrasbourgresolutions.html>> accessed 14 May 2018; European Congress on People with Disabilities, ‘Madrid Declaration’ (March 2002) <<http://ifglobal.sitehosting.be/uploads/documents/Madrid%20Declaration%202002.pdf>> accessed 18 July 2019.

¹⁴¹ Zarb, ‘Road to Inclusion’ (n27); Jolly (n65).

¹⁴² Mason, ‘Back to Basics’ (90) pages unnumbered.

¹⁴³ Morris, ‘Independent Living and Community Care’ (n27). There was also concern about a lack of understanding, or ‘misuse’ of the term ‘personal assistance’ (and ‘independent living’). Jolly (n65).

¹⁴⁴ Evans, ‘Understanding Our Past’ (n61) 4.

In the wider texts there was discussion of difficulties emerging in relation to direct payments when these became mainstreamed and entangled with the existing mechanisms of social care.¹⁴⁵ Different but connected difficulties were articulated, including resources,¹⁴⁶ bureaucracy¹⁴⁷ and public sector control.¹⁴⁸ This was articulated most strongly by Mason:

We dreamed a dream: the means to be enabled access to work, rest and play through funding to purchase and organise personal assistance. Along comes legislation which fits things into Government criteria and things turn out different to the dream.... What has happened is that direct payments is seen as just another means of providing social welfare. At the basic level it is seen in the same category as ...an auxiliary nurse getting you up and putting you to bed¹⁴⁹

Mason argued that direct payments, in this neutralised form, reinforced narratives and mechanisms of care, vulnerability and dependency, and that this amounted to the 'theft' of independent living.¹⁵⁰

These difficulties had been recognised from the early stages. Certain authors suggested solutions including handing over direct payment structures to DPOs to run,¹⁵¹ and the development of a European funding stream to provide core funds to

¹⁴⁵ When they were placed on a legislative basis, direct payments were incorporated into the existing social care mechanisms and subject to the assessment process that already existed. There were therefore fundamental distinctions between direct payments as they were conceived by disabled activists – in which the individual receives a sum of money that meets their own self-identified and self-assessed needs – and the model that now exists, in which assessment is the duty of the local authority, needs are subject to eligibility criteria, and responses funded by the local authority. The implications of this are considered succinctly and fully by Pearson. Charlotte Pearson, 'Independent Living' in Nick Watson, Alan Roulstone and Carol Thomas (eds), *Routledge Handbook of Disability Studies* (Routledge 2012).

¹⁴⁶ Davis, 'Power' (n30); Morris, 'The Meaning of Independent Living' (n32); Evans, 'Understanding Our Past' (n61); Zarb, 'Road to Inclusion' (n27).

¹⁴⁷ Mason, 'Back to Basics' (n90).

¹⁴⁸ Evans, 'Understanding Our Past' (n61); Zarb, 'The Road to Inclusion' (n27).

¹⁴⁹ Mason, 'Back to Basics' (n90) pages unnumbered. Mason also stated: 'But it not just that direct payments are not independent living and that the term 'independent living' has been stolen...'. A similar point is made by Ken Davis, albeit not connected specifically to discussion of direct payments. Davis, 'Power' (n30).

¹⁵⁰ Mason, 'Back to Basics' (n90).

¹⁵¹ Barnes suggested that this would free direct payments from 'local authority regulation and control'. Barnes, 'Independent Futures' (n83) 25-26.

DPOs working on independent living and personal assistance.¹⁵² Both Zarb and Morris suggested that the establishment of a right to independent living would assist in overcoming these difficulties.¹⁵³ There was however, limited detailed consideration of how direct payments could be definitively divorced from the mechanisms that accompany the use of public monies or the complexity of resourcing decisions.¹⁵⁴ It should be noted, however, that the absence of these discussions in the dataset texts did not indicate or imply that they did not exist elsewhere.¹⁵⁵

Other enablers of independent living were also important in the texts. Peer support was widely discussed and referenced a similar number of times as direct payments.¹⁵⁶ Like personal assistance, peer support was one of the original ‘pillars’ of independent living.¹⁵⁷ CILs were central to peer support and acted as ‘communities of choice’.¹⁵⁸ They were constructed as locations for the exchange of ideas, information, training and support, for the development of solidarity, empowerment and the movement,¹⁵⁹ for lobbying work with governments,¹⁶⁰ and the means of reaching individuals who had not yet come into contact with the idea or

¹⁵² Jolly (n65).

¹⁵³ Zarb, ‘The Road to Inclusion’ (n27); Morris, ‘Independent Living and Community Care’ (n27). Note that Zarb considered that it was essential first to change the underlying discourses of dependency.

¹⁵⁴ There was discussion as to how available monies could – and should – be redirected from traditional services to direct payments, or from institutional living to support that enabled independent living. However, there was little discussion of, for example, the problem of finite resources, of whether and how eligibility criteria should be replaced; of the fact that where public sector money is involved, there must at some point be a decision on what levels of funding – both in general and in relation to one individual – are available; of what represents a decent standard of living and how this can be adjudicated; or the inequalities that might arise when articulate and empowered individuals and the most disempowered are seeking access to the same resources (although peer support and advocacy were identified as essential pillars of independent living).

¹⁵⁵ Some texts written by authors who were also represented in the Anglo-British DPM dataset have given detailed consideration to such matters. For example, Colin Barnes and Geof Mercer, *Independent Futures: Creating User-Led Disability Services in a Disabling Society* (Policy Press 2006).

¹⁵⁶ Peer support was discussed in 30 extracts, excluding references to CILs and other DPOs.

¹⁵⁷ See Chapter 2, section 4 for explanation of the pillars of independent living. These occurred in various formats, developing from five, to seven, to nine, to 11 to 12. Peer support was one of the original five pillars and did not vary, although it was expanded.

¹⁵⁸ Evans noted that peer support was a core theme of the Berkeley CIL. Evans, ‘The Role of CILs’ (n60). For discussion of communities of choice, see Chapter 4, section 2.1.

¹⁵⁹ ‘In broad terms CILs are organisations run, managed and controlled by disabled people that provide a range of services designed to give disabled people and their families support to live independently in the community. In so doing they have played a pivotal role in disabled people’s struggle for equal rights and citizenship.’ Barnes, ‘Independent Futures’ (n83) 8-9.

¹⁶⁰ ‘CILs are run, controlled and organised by disabled people to offer training, peer support and other services to disabled people, they also engage in work with local, national and European governments to raise awareness and challenge issues that relate to the services and rights of disabled people.’ Jolly (n65) 5.

practice of independent living.¹⁶¹ They were also positioned as places in which disabled people, rather than professionals, held the expertise,¹⁶² and in which the dominance of professional knowledge could be countered.

There was also discussion of ‘co-production’ – or the involvement or partnership of disabled people in the development and management of services. Co-production was rarely referenced in the extracts, but in the wider texts it appeared as a consistent theme from the earliest texts onwards. Methods of co-production found in the broader texts included engagement in democratic, management and decision-making structures,¹⁶³ involvement in consultation on policy, legislation and strategy,¹⁶⁴ inclusion in decision-making,¹⁶⁵ and the investment in and devolvement of resources to CILs and other DPOs.¹⁶⁶ Co-production was articulated as a manifestation of the principle of ‘nothing about us without us’.¹⁶⁷ Beresford argued that it was a means of equalising the relationship between the individual and state agencies,¹⁶⁸ and Morris noted its importance in shifting from a narrative of paternalism or ‘doing to’ disabled people to one of shared responsibility.¹⁶⁹

¹⁶¹ ‘We worked on this so that we could extend the opportunities of Direct Payments to other disabled people, living in areas that had previously not provided any other Independent Living service.’ Evans, ‘Understanding Our Past’, 6.

¹⁶² More specialist topics ...and other such training courses, often of a more individual peer counselling nature, may be better suited to the specialist setting of a CIL ... where the "experts" [are]. HCIL, ‘HCIL Papers’ (n38) pages unnumbered.

¹⁶³ UPIAS, ‘Fundamental Principles’ (n15) set out a vision of a system in which disabled people would sit on panels, alongside other experts, to consider ways in which social hurdles that exclude disabled people could be overcome. This was seen as a means of placing disabled people at the centre of social development, with non-disabled people acting in their service, as a way of building solidarity, confidence and skills on the part of disabled people, and as a means of building a more generally inclusive society. Ken Davis, who was a member of UPIAS, shared these ideas, see Davis, ‘Notes’ (n138) and discussion in Chapter 8, section 3.1.

¹⁶⁴ HCIL, ‘HCIL Papers’ (n38); Barnes, ‘Independent Futures’ (n83); Disability Rights UK, ‘Consultation Response on “Fulfilling Potential: Disability Strategy” (9 March 2012), <<https://www.disabilityrightsuk.org/sites/default/files/pdf/fulfillingresponse.pdf>> accessed 2 January 2017. Certain of the texts demonstrated this directly, comprising written responses to governmental initiatives. See: BCODP, ‘Comment on the Report of the Audit Commission’ (n6); Disability Rights UK, ‘Joint Committee on the Draft Care and Support Bill: Written Submission’ (11 January 2013) <<https://www.disabilityrightsuk.org/sites/default/files/pdf/jointcommitteeresponse.pdf>> accessed 2 January 2017.

¹⁶⁵ DRUK, ‘Consultation Response’ (n164).

¹⁶⁶ BCODP, ‘Comment on the Report of the Audit Commission’ (n6); Barnes ‘Independent Futures’ (n83), DRUK ‘Consultation Response’ (n164); Inclusion London, ‘Evidence of Breaches’ (n82); Jolly (n65) argued that such organisations should be paid by the state for their expertise and involvement.

¹⁶⁷ DRUK, ‘Consultation Response’ (n164) 6; Morris, 2011, 13.

¹⁶⁸ Beresford, *What Future for Care?* (n95).

¹⁶⁹ Morris, *Rethinking* (n33) 13.

A final, vital, enabler of independent living was access. This was specifically cited a similar number of times as direct payments.¹⁷⁰ Access appeared particularly in relation to the pillars of independent living,¹⁷¹ and was connected to the general environment,¹⁷² specific elements of the environment, such as one's home or public transport;¹⁷³ and items that were particularly relevant to disabled people, such as information and advocacy.¹⁷⁴ It was also cited in relation to elements of citizenship, such as rights.¹⁷⁵ Access was connected to the idea of equality:

The general objective is that of personal autonomy or self direction in a world whose attitudes and structures would enable physically and intellectually impaired people to enjoy equal opportunity with their ablebodied peers.¹⁷⁶

As noted in section 3.2, above, access underwrote the narrative of social agency and was implicit in relation to this. It was also a core aspect of the social model of disability, upon which independent living was built.¹⁷⁷ Throughout the documents, access was therefore a latent as well as an explicit idea, both stated and assumed as an underpinning principle or need if independent living was to be achieved.

¹⁷⁰ Access was cited as an enabler in 37 extracts.

¹⁷¹ In her list of 12 pillars or 'basic needs' for independent living, for example, Morris includes: 'full access to our environment', 'a fully accessible transport system', 'accessible adapted housing', 'appropriate and accessible information', and 'appropriate and accessible health care provision'. Morris, 'Independent Living and Community Care' (n27) 428.

¹⁷² 'Independent Living is the term used by many disabled people to express a general concept, within which is implied a further definition in respect of the particular issue of assistance with daily living. The general objective is that of personal autonomy or self direction in a world whose attitudes and structures would enable physically and intellectually impaired people to enjoy equal opportunity with their ablebodied peers.' HCIL, 'HCIL Papers' (n38) pages unnumbered.

¹⁷³ Morris, 'Independent Living and Community Care' (n27).

¹⁷⁴ 'The DRC believes that all disabled people should have a right of access to advocacy if they need it. All disabled people should also have a right to support to meet their access, information and communication needs.' Zarb, 'Road to Inclusion' (n27), 197.

¹⁷⁵ '[The pillars] are areas in which disabled people have requirements, over and above those of non-disabled people, which must be met if they are to experience equal access to human and civil rights.' Morris, 'Independent Living and Community Care' (n27) 429.

¹⁷⁶ HCIL, 'HCIL Papers' (n38) pages unnumbered.

¹⁷⁷ See Chapter 2, section 3.

4.4.1. Enablers of independent living: Discussion

It is indicated in Chapter 4 that one of the repeated themes explored by authors using counter-narrative theory was that of identities damaged by master narratives of deficit – that the outgroup is in some way deficient when compared with the ingroup. This has a particular resonance for disabled people, whose defining characteristic as an ‘outgroup’ is the existence of some form of embodied distinction which has an *actual* impact on functioning and which is typically understood (by the ingroup) as ‘deficit’. The particular value of the enablers of personal assistance and direct payments was their ability to surmount ‘deficit’ in ways that gave effect to the identity created by the narratives of personal and social agency. Personal assistance and direct payments were not just alternative means of providing support in the activities and needs of daily life; they were the means by which people were able to exercise self-determination and establish a meaningful personal and social existence. It was notable that the need for support was entirely unquestioned. Indeed, the existence of personal assistance as one of the consistent pillars of independent living demonstrated that support was considered fundamental in achieving independent living. This emphatically reversed the view that social care represented a form of undesirable dependency. Assistance was framed instead as an essential means of liberation.

These support mechanisms also had a direct impact on the status of disabled people. Direct payments and personal assistance transformed disabled people from objects of ‘care’ into employers of people carrying out tasks under their direction. The language of ‘assistance’, and particularly ‘personal assistance’ drew parallels between disabled people and other managers who require support in their working and daily lives.¹⁷⁸ As well as tackling the problem of deprivation of opportunity, direct

¹⁷⁸ The language of ‘personal assistance’ also reflects a social reality. Where individuals are using direct payments to recruit and employ a number of individuals to act as personal assistants under their management and direction, ‘care’ may not be the best descriptor of the activities and relationships in place. Activists also pulled away from the language of ‘services’, which was considered to reflect state-controlled and inflexible provision. In addition to ‘assistance’, the term ‘support’ was favoured. See, for example, Jenny Morris, ‘Personal Budgets and Self-Determination’ (Blogpost, 24 April 2014) <<http://jennymorrisnet.blogspot.it/search?updated-max=2014-07-14T12:04:00%2B01:00&max-results=7&start=7&by-date=false>> accessed 16 October 2015.

payments and personal assistance thus also acted to reject the problem of the infiltrated self, enabling disabled people to see themselves as actual or potential people of worth and social standing beyond that of recipient. As employers, disabled people were also able to evade the problem of being subject to control by informal carers.

While certain of the enablers of independent living – particularly access, peer support and co-production – emphasised collective values, the central mechanisms of direct payments and personal assistance are highly individualised. They require funding to be individually allocated and devolve responsibility to individuals for the expenditure of that money. Direct payments and personal assistance therefore ‘activated’ the individualism intrinsic to the narratives of personal and social agency, transforming this inherent aspect into an actual and definite matter. These mechanisms were devised for the specific purpose of enabling individuals to act on their personal agency and translate life choices into the lived reality, enabling each to live life in his or her own way. This was a characteristic from the earliest stages – while the people involved in Project 81 had worked as a group to achieve their ambitions, the mechanisms they devised enabled them to break out of Le Court as *individuals*, each on their own terms.¹⁷⁹ The enablers of direct payments and personal assistance effectively entrenched the individualism in independent living as a concrete idea within public sector responses to need. Collective and collaborative approaches to direct payments, such as pooling, or the organisation of cooperatives to facilitate their use were discussed, but not widely pursued in these particular

¹⁷⁹ The stories of those involved in Project 81 (see Chapter 2, section 4) demonstrate how differences of attitude and interests resulted in the members of the group deciding to live separately rather than together, as had originally been envisaged. See, HCIL, ‘Project 81: One Step On’ (undated) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/HCIL-one-step-on.pdf>> accessed 7 December 2017. For example: Liz Briggs stated: ‘I intended being one of the three people to live in Oxford Street until I saw the place. I did not like the building, but the others were so enthusiastic about it I thought there was something wrong with me. Also as we discussed details I found that our ideas of care were totally different. I felt that I needed to have someone around me all the time, whereas the others did not.’; Philip Mason stated: ‘What I saw convinced me that I could make it on my own, and that I would prefer to have the greater choice this gave. It was a big turning point. I was sure I had to do my own thing.’; John Evans stated: ‘I was building on Liz and Philip’s experiences. My vision was coloured by what they had done, but at the same time I knew that the details of my proposal were going to be quite different. I tried to imagine a system that would work for me.’ (Pages are unnumbered in this document.)

texts.¹⁸⁰

Direct payments also facilitated a construction of disabled people as consumers and administrators of public funds that was valuable to the ideology of public sector marketisation being contemporaneously pursued at Westminster. This adjacency created lobbying opportunities, and it is highly likely that the confluence between direct payments and Westminster narratives of individualism and marketisation was influential in the campaign for direct payments to be placed on a sound legislative footing. This also had the impact of aligning the disabled people's movement to a political narrative of welfare state residualisation. As Morris stated:

The [direct payments] legislation, passed by a Conservative government in 1996, fitted in with an agenda which sought the privatisation of services and an undermining of public sector trade unions. While disabled people's organisations did not support such policies, we did – when making the case for direct payments – use language which fitted well with the individualist political framework which was becoming more and more dominant.¹⁸¹

This adjacency is now widely acknowledged and difficulties arising from it have been extensively explored.¹⁸² They include the use of narratives of the disabled people's movement by successive governments to further the individualistic and broadly neoliberal agenda described earlier in this thesis. Direct payments had a particular value for this project. In 2011, Morris argued that independent living has been

¹⁸⁰ HCIL, 'HCIL Papers' (n38), pages unnumbered. HCIL examined a number of collaborative approaches, including approaches to direct payments, but these were not broadly discussed in the documents in this dataset. Discussions of how direct payments might be used in cooperative ways have certainly been explored and discussed elsewhere. See in particular, Alan Roulstone and Se Kwang Hwang, 'Disabled People, Choices and Collective Organisation: Examining the Potential of Cooperatives in Future Social Support' (2015) 30(6) *Disability & Society* 849, citing Jenny Fisher, Mary Rayner and Sue Baines, 'Personalisation of Social Care and Health: A Co-Operative Solution. Manchester' (Cooperative UK 2011) and Jon Glasby and Mick Taylor, 'It's All at the Co-Op' (*Community Care* 2 February 2006) <<http://www.communitycare.co.uk/2006/02/02/its-all-at-the-co-op/>> accessed 28 July 2019.

¹⁸¹ Morris, *Rethinking* (n33) 3.

¹⁸² See, for example *Ibid*; Colin Barnes and Geof Mercer, *Independent Futures: Creating User-Led Disability Services in a Disabling Society* (Policy Press 2006); Mike Oliver, 'Choice, Control and the Dangers of the Free Market' (*Disability Now*, April 2013) <<http://www.disabilitynow.org.uk/article/choice-and-control-and-dangers-free-market>> accessed 27 May 2015. Pearson, 'Independent Living' (n145).

‘colonised and corrupted’ by successive UK governments and that direct payments needed to be re-grounded in a collective approach if the ‘individualist framework’ was not to consume them.¹⁸³

This raised the question of how the integrity and character of direct payments could be preserved within a system built on the master narratives that independent living was developed to counter. The insertion of direct payments into community care structures had the potential both to compromise the mechanism and to bolster these master narratives through the incorporation and potential neutralisation of a critical fragment of the counter-narrative. In her analysis, Nelson suggests that gaps can exist within and between master narratives that allow a counter-narrative to take hold.¹⁸⁴ Nelson does not identify this as a possible weakness of *counter*-narratives, although the same potential problem exists. The lack of detailed discussion in the texts as to how direct payments and personal assistance could remain uncompromised while in a close relationship with a system built upon narratives of deficit, dependency and care, and how adequate individual support could be available without restriction in a resource-driven environment, opened up gaps in the counter-narrative that had potential to cause difficulty. Indeed, for sound campaigning reasons, the disabled people’s movement argued that direct payments were a cheaper – or certainly a financially efficient – form of support provision.¹⁸⁵

5. Independent living in the Anglo-British texts and in the CRPD

Since its incorporation and ratification, the UNCRPD has provided a series of legal provisions in relation to disability – including independent living – and has become a

¹⁸³ Morris, *Rethinking* (n33) 10, citing B Sapey and J Pearson, ‘Do Disabled People Need Social Workers?’ (2004) 11(3) *Social Work and Social Sciences Review*, 52.

¹⁸⁴ Nelson (n1), 165-167.

¹⁸⁵ Oliver, ‘Older People’ (n74). Arguments about the cost benefits of independent living are as old as independent living itself. See Jean Simkins, ‘The Value of Independent Living’ (Spinal Injuries Association, undated but filed in the Leeds University Disability Archive in 1978) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/simkins-the-value-of-ind-living.pdf>> accessed 19 February 2019. See also Gerry Zarb and Pamela Nadash, ‘Cashing in on Independence: Comparing the Costs and Benefits of Cash and Services’ (BCODP 1994) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Zarb-cashing-in-on-indep.pdf>> accessed 19 February 2019.

central focus of disability campaigning in both the UK and globally. Given the obligations on states parties to progressively realise rights under the Convention,¹⁸⁶ the UNCRPD has ramifications for all those developing domestic policy and law that impacts on disability matters. It is not the purpose of this thesis to examine independent living in the context of the provisions of the UNCRPD in detail, and that discussion exists elsewhere.¹⁸⁷ For contextual reasons, however, it is important to consider the extent to which the model of independent living constructed in the UK is connected to the rights enacted by the UNCRPD. This short section therefore considers whether and how the model of independent living developed in the Anglo-British context is reflected in and supported by the UNCRPD and particularly Article 19.

Article 19 is set out in full in Chapter 2, section 4. The essential entitlement that it creates is the equal right of disabled people to live in the community, with choices equal to others, and an expectation of the full inclusion and participation of disabled people in community life. States are required to support this by ensuring three things:

- a. That disabled people can choose where they live and with whom, and are not forced into a particular living arrangement;
- b. That disabled people have access to a range of support services, including personal assistance, to enable them to live in the community and take part in community life;
- c. That universal community services and facilities meet the needs of and are equally accessible to disabled people.

¹⁸⁶ In relation to devolved matters, the UK Government is entitled to rely on the devolved administrations to ensure that rights under the UNCRPD are progressively realised. Joint Committee on Human Rights, *Implementation of the Right of Disabled People to Independent Living* (2010-12, HL 257, HC 1074).

¹⁸⁷ For example, T Hammarberg, 'The Right of People with Disabilities to Live Independently and be Included in the Community' (Issue Paper, Council of Europe Commissioner for Human Rights, 2012) <<https://rm.coe.int/the-right-of-people-with-disabilities-to-live-independently-and-be-inc/16806da8a9>> accessed 10 July 2019; Arlene Kanter, *The Development of Disability Rights under International Law: From Charity to Human Rights* (Routledge 2015); János Fiala- Butora, Arie Rimmerman, and Ayelet Gur, 'Article 19: Living Independently and Being Included in the Community' in Ilias Bantekas, Michael Stein and Demetres Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018).

Article 19 is supported by a general comment, which expands on the content of the Article.¹⁸⁸

Although Article 19 was not devised to bring the Anglo-British model of independent living into the CRPD,¹⁸⁹ it contains the essential core fragments identified in this chapter that contribute to the repair of the identity and agency of disabled people. With the exception of an explicit reference to disabled people having control over their life and support, the central ideas of personal and social agency, and equality and rights are all very clearly present. The lack of a reference to control in the Article itself is mitigated by the General Comment, which carries a strong focus on this aspect and repeatedly uses the phrase ‘choice and control’ (or similar).¹⁹⁰

Community living, personal assistance, equality and access are all critical elements of Article 19. The focus found in the Anglo-British DPM texts on living ‘ordinary’ lives is not explicit, but this is again offset by the content of the General Comment which brings this element to the fore. Article 19 therefore enshrines the core elements of independent living as it is created through the combined fragments found in the Anglo-British texts. It is bolstered and supported by other Articles within the UNCRPD. Article 3 (General Principles) includes the principles of self-determination, ‘full and effective participation and inclusion in society’ and equality of opportunity; Article 5 focuses on equality, Article 8 (on awareness raising) includes a requirement to challenge stereotypes around disabled people) and Article 9 holds various requirements relating to accessibility. Article 12 creates the right of equal recognition before the law.

¹⁸⁸ Committee on the Rights of Persons with Disabilities, ‘General Comment No. 5 (2017) on Living Independently and being Included in the Community’ (October 2017), available from: United Nations Office of the High Commissioner of Human Rights, ‘Committee on the Rights of Persons with Disabilities’ (undated) <<https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>> accessed 10 July 2019.

¹⁸⁹ See Chapter 2, Section 4.

¹⁹⁰ The first sentence of the General Comment (n188) is: ‘Persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives’. Paragraph 2 goes on to state: ‘Article 19 of the Convention on the Rights of Persons with Disabilities recognizes the equal right of all persons with disabilities to live independently and be included in the community, with the freedom to choose and control their lives’. Other such references occur throughout the document.

Article 19 itself is recognised as both one of the pivotal provisions of the UNCRPD¹⁹¹ and one of the provisions – particularly in conjunction with Article 12 – that is critical in establishing the ‘paradigm shift’ within the UNCRPD of constructing disabled people as rights-holding and equal individuals rather than ‘objects’ of care and management.¹⁹² It therefore encapsulates not simply the core elements of independent living as it is constructed in the movement, but also the same purpose of narrative reconstruction and repair of the identity and agency of disabled people that is identified in this thesis. Essentially, the UNCRPD can itself be characterised as an exercise in counter-narrative development. It is worth noting, however, that the particular focus in Article 19 on living arrangements may have the impact of equating ‘living independently’ – or independent living – particularly with those arrangements, rather than the broader aspect of self-determination and equal opportunities in *all* aspects of life.

6. Conclusion

This chapter has explored how independent living was developed by disabled activists to counter master narratives of otherness, deficiency, vulnerability and ‘care’. Certain core fragments of independent living are identified which produce in the counter-narrative four essential ‘threads’ that together accomplish the narrative repair of the identity and agency of disabled people – personal agency, social agency, equality and rights, and the key enablers of direct payments, personal assistance and access. Independent living is established as a powerful counter-narrative that tackles the problems of the deprivation of opportunity and the infiltrated self. Certain potential or actual difficulties within independent living as a counter-narrative have also been identified, particularly around the enablers of direct payments and personal assistance.

In the Welsh context, in which social care structures have essentially been inherited, efforts by the Welsh Government to incorporate independent living into policy and

¹⁹¹ Hammarberg (n187); Kanter (n187).

¹⁹² Fiala-Butora, Rimmerman, and Gur (n187).

law in this field would be likely to be influenced by the process of uptake in Westminster, but also by models of independent living developed and promoted by the disabled people's movement in Wales. The following chapter therefore examines whether and how the fragments identified in this chapter appear in the texts in the Welsh DPM dataset, and the model of independent living that is constructed in those texts.

Chapter 7: Fragments of independent living in the Welsh DPM texts

1. Introduction

In the previous chapter, various fragments and four distinct threads of the independent living counter-narrative were identified, and their contribution to the narrative repair of the identity and agency of disabled people was examined. In the devolved Welsh context, any incorporation of independent living into Welsh Government policy and Welsh legislation would also draw on the model of independent living as it was understood and embraced in Wales. It was therefore necessary to understand whether the disabled people's movement in Wales had developed or adapted independent living for the Welsh context. The potential for such developments was apparent from the 2010 Disability Wales campaign called 'Independent Living NOW! One of the aims of this campaign was:

raising awareness and understanding of what Independent Living means for disabled people in Wales.¹

It was clear, therefore, that independent living was a matter of importance to disabled activists in Wales and that these activists anticipated that there might be a distinct understanding of independent living in the Welsh context. This chapter examines the fragments of independent living in the Welsh DPM texts to establish whether and how far the movement in Wales has created its own distinct form of independent living, and what similarities and distinctions exist between the

¹ Disability Wales / Anabledd Cymru, 'Manifesto for Independent Living' (2011) <http://www.disabilitywales.org/wordpress/wp-content/uploads/Manifesto_for_IL_E.pdf> accessed 11 November 2016, 2.

construction of independent living in the Welsh texts and the model formed by the Anglo-British movement.

In this chapter there are two main parts which examine the content of independent living in the Welsh DPM dataset texts. The first of these considers the definitions and priorities of independent living in the Welsh texts and the second is focused on the fragments of independent living that were explored in the previous chapter. These sections are preceded by an introduction to the Welsh texts that sets out some broad observations on their content and characteristics.

2. The texts in the Welsh DPM dataset

This chapter is significantly shorter than the preceding one. The reason for this was the small number of texts emanating from the disabled people's movement in Wales. The nature and development of the Welsh movement is outlined in Chapter 3, section 4. Examination of this movement – and the texts produced by it – demonstrated that it was distinct from the Anglo-British movement in three core respects – it was smaller, its history was less clearly connected with grassroots activism, and there were few 'theorists' among Welsh disabled activists. There was also a certain lack of separation from state agencies, although this was also a feature of certain organisations in the Anglo-British context.

These points are not intended as negative statements and should not be understood as such. They reflect the fact that a separate movement in Wales has not always been necessary and that the development of a distinct movement in Wales is a relatively recent phenomenon. This is true of the third sector generally in Wales. In terms of civil society, the border between England and Wales has always been, and remains, porous, reflecting the facts that Wales has never been a distinct legal jurisdiction and the Welsh governance institutions are still young and limited in their size and scope. It is noted in Chapter 3 that many third sector organisations in Wales are offshoots of organisations that developed in the broader UK-wide, or England- and Wales-wide arena. In this fluid context, disabled activists in Wales would be

aware of, borrow from, and contribute to the development of activism and ideas in the broader UK movement. Similarly, the social care policy and system to which independent living reacted was – prior to devolution – common to both countries, and the master narratives that independent living countered were also shared. The development of a distinct movement in Wales was therefore not inevitable.

As a result, the Anglo-British movement, and the development of independent living within it, frame and provide the roots and context for activism in Wales on independent living and the social model. The shared heritage was demonstrated by matters such as the former inclusion of the 12 pillars of independent living on the website of Disability Wales in the same format as they appear in many Anglo-British documents.² Given these common roots, at the outset of this project, there were questions as to whether substantial texts on independent living would yet have emerged from Welsh activists. Difficulties in sourcing texts from the disabled people's movement in Wales were indeed encountered, and are outlined in Chapter 5, section 4.2.

The Welsh texts that were found shared particular characteristics. They were less detailed and complex, and less rich in their content and expression than many from the Anglo-British database. On examination, this was considered to be for various reasons. Firstly, the texts were authored relatively late and by organisations rather than individuals. It is noted in the previous chapter that in the Anglo-British dataset, such texts were typically less explicit about the content of independent living and more moderately expressed than earlier documents and those authored by individuals.³ Secondly, the Welsh texts were produced for political and governmental audiences that were significantly less sophisticated than those in Westminster.⁴

² Disability Wales, 'The 12 Pillars of Independent Living' (undated) <<http://www.disabilitywales.org/social-model/independent-living/the-12-pillars-of-independent-living/>> accessed 6 January 2018. (This page was removed from the Disability Wales website during its renovation in spring 2018). On one page the pillars were described as the 'Disability Wales "12 Pillars of Independent Living"'. Disability Wales, 'The Welsh Government Framework for Action on Independent Living' (*Disability Wales*, undated) <<http://www.disabilitywales.org/toolkit/why-make-planning-more-inclusive/the-welsh-government-framework-for-action-on-independent-living/>> accessed 14 December 2017.

³ Section 3.

⁴ The youth of, and the restrictions on, the National Assembly for Wales and the Welsh Government are discussed in Chapter 3, particularly sections 2 and 3.

Policy makers in Wales were working in developing governance structures that were grappling with swiftly increasing powers with limited experience and capacity. Such an audience would need ‘broad brush’ and relatively basic information rather than complex detail that built on a level of shared knowledge developed through decades of lobbying.⁵ Finally, the movement in Wales lacked the well-known and established academic or theoretical activists that historically formed part of the broader movement and the typically analytical texts that were authored by such individuals.⁶ This was simply the result of the fact that by geographical accident such authors tended to be situated in England.

In summary, therefore, the activity of the Anglo-British movement was as relevant to developments in Wales as to developments in England. The findings set out in the previous chapter relate to the Welsh context as well as the Anglo-British setting, and independent living as constructed in the Anglo-British texts is the root of independent living in Wales. The key question in the examination of the Welsh texts was whether there were distinctions or new directions in how independent living was constructed in the Welsh context, bearing in mind this common heritage.

3. Definitions and priorities of independent living in the Welsh texts

Two definitions of independent living were found in the Welsh texts: a detailed description that formed part of the 2011 Disability Wales *Manifesto for Independent Living* (‘the *Manifesto*)⁷ and a short ‘slogan’ around independent living that also

⁵ For example, the lobbying which led to the development of the Disability Discrimination Act 1995 and the incorporation of direct payments into legislation.

⁶ This statement is not intended to imply that academic input is required for a grassroots social movement to be effective, or that there are no activists in Wales who are capable of this input. Non-academic activists in the disabled people’s movement, particularly in its early stages, produced highly complex analysis.

⁷ n1. This emerged from the Disability Wales ‘Independent Living NOW!’ campaign which was instrumental in persuading the Welsh Government to develop a strategy for independent living. See Chapter 2, section 4.

appeared in the *Manifesto* and was later cited as a definition by disability related organisations⁸ and the Welsh Government.⁹ The longer definition stated:

Independent Living is an idea that helps with understanding the barriers that disabled people face in their everyday lives. It shows what needs to be done to ensure that disabled people are valued and treated with the same respect as other citizens. Independent Living does not mean that disabled people should have to live in isolation, do everything for themselves or be completely independent of services. It means:

- removing the barriers that prevent full social and economic participation in mainstream society, and
- ensuring that disabled people have the same freedom, choice, dignity, control and opportunities as any other citizen – at home, at work and in the community.

The right to Independent Living is set out in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which recognises “the equal right of all disabled persons to live in the community, with choices equal to others”.¹⁰

The shorter definition read:

Independent living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves.¹¹

⁸ Letter from Vin West on behalf of Arfon Access Group / Grwp Mynediad Arfon to Sarah Beasley, Clerk to Health & Social Care Committee, (15 March 2013) (accepted as a response to the consultation on the Social Services and Well-being Wales Bill) <www.senedd.assembly.wales/documents/s15313/SSW%2043%20Arfon%20Access%20Group.pdf> accessed 2 January 2017, 2.

⁹ Welsh Government, ‘Framework for Action on Independent Living’ (2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018, 7.

¹⁰ Disability Wales, ‘Manifesto for Independent Living’ (n1) 6.

¹¹ Ibid 6.

The longer definition of independent living contained all the core fragments of independent living that were found in the Anglo-British texts and clearly drew on the well-known DRC definition.¹² Personal agency was expressed through reference to the definitional fragments of choice and control. The central elements of social agency including the construction of disabled people as active citizens carrying out typical social roles was also set out. Independent living was framed as a right through reference to Article 19, and the principle of equality was repeatedly stated ('the same respect', 'the same freedom', 'other citizens'). A notable further feature of this Welsh definition was the implicit reference to and the foregrounding of the social model of disability – in terms of barrier removal – as a central principle. This was distinct from the definition created by the DRC, in which the social model was not obviously referenced.¹³

The shorter 'definition' of independent living – which was found in other texts in the Welsh dataset and appeared to be the definition then taking root in Wales¹⁴ – was much less explicit and gave scope for a more fluid understanding. While it strongly articulated the notions of choice, empowerment and a meaningful life, it did not make explicit certain core features, including equality, control, integration into the community, the distinction between self-determination and self-reliance, or the social model. One matter that was omitted from both definitions was an explicit statement that independent living was a creation of the disabled people's movement, developed as a form of resistance. It is likely that this was so apparent to activists that such a statement was not considered necessary.¹⁵

¹² See Chapter 2, section 4.

¹³ There was no implicit or explicit reference to the social model in the description of independent living created by the DRC which is now frequently used as a definition. However, the social model is referenced both implicitly and explicitly later in the document in which this definition first appeared. Disability Rights Commission, 'Policy Statement on Social Care and Independent Living' (October 2002), provided to the author by e-mail from the EHRC 28 May 2015.

¹⁴ It is noted above that the use of this short statement as a 'definition' was cited in both the Welsh Government 2013 *Framework for Action on Independent Living* and other documents in the dataset of texts from the disabled people's movement in Wales. The draft of the document that will replace the 2013 *Framework* does not use this short statement. It provides a new explanation of independent living which has strong similarities to the DRC definition. See discussion in Chapter 12.

¹⁵ It should be noted that statements to this effect were also absent from the most recent texts in the Anglo-British DPM dataset, in which independent living was effectively presented as a concept that was mutually understood between author and reader.

The Disability Wales Manifesto for Independent Living also set out six priorities for independent living, established through discussion with individuals and organisations across Wales. These priorities were:

1. Improved access to information, advice, independent advocacy and peer support services for all;
2. Availability of accessible and supported housing to meet individual requirements;
3. A comprehensive range of options and genuine choice and control in how personalised care and support is delivered;
4. Improved access to Person Centred Technology (aids & equipment);
5. A barrier free transport system, including all modes of transport;
6. Enabling access, involvement and social, economic and cultural inclusion for all disabled people.

It is noted above that Disability Wales has in the past provided information on the 12 pillars of independent living. These did not appear in the Independent Living Manifesto or the other texts, and it appeared that these six priorities were performing a similar function for the Welsh context.¹⁶ There were both similarities and distinctions between the Welsh priorities and the 12 pillars. Access was a fundamental principle that both stood alone and underpinned various other elements. Housing, transport, information, technical aids and equipment, peer counselling, and advocacy were all also included, although access to health care was absent.¹⁷ Employment, education and income were also not expressly referenced, although these were implied by the priority of ‘access, involvement and social, economic and cultural inclusion for all disabled people’. Most significantly, personal assistance – which was one of the original and consistently cited pillars of independent living – was not mentioned in the Welsh priorities. In contrast, support in daily living activities was envisaged as:

¹⁶ Indeed, these principles were elsewhere stated by Disability Wales to be ‘based on Disability Wales “12 Pillars of Independent Living”’. Disability Wales, ‘Welsh Government Framework’ (n2).

¹⁷ This is not always included in the references to the pillars of independent living in the Anglo-British context. While Morris included it, it is a relatively recent addition, and is not always articulated. See Chapter 2, section 4.

A comprehensive range of options and genuine choice and control in how personalised care and support is delivered.

This indicated that the connection between independent living and social care support was envisaged in a distinct form in the Welsh texts. While choice and control over support was emphasised, the movement in Wales appeared open to the provision of social care support in various forms. The language of ‘personalisation’ also echoed the UK government agenda for social care in the English policy context. These matters are explored in detail below.

4. The fragments and narratives of independent living in Wales

This section considers the fragments that were explored in the texts from the Anglo-British DPM dataset in the threads of ‘personal agency’, ‘social agency’ and ‘equality and rights’, and the enablers of independent living. Given the small number of documents in the Welsh dataset and their generally less complex content, there is greater reliance in this analysis on the content of the texts beyond the extracts in which the phrase ‘independent living’ occurred. As with the discussion of the Anglo-British DPM dataset texts, where the analysis relates to the wider documents, this is explicitly stated. A table setting out the number of references to specific fragments of independent living in the Welsh DPM texts is provided in Appendix 7.

4.1. Personal agency

Personal agency in the form of self-determination had a similar importance in the Welsh texts as in the Anglo-British DPM dataset. Self-determination was strongly expressed in the short ‘definition’ of independent living, discussed above, which appeared on four occasions. However, as that definition demonstrates, self-determination was expressed differently in the Welsh extracts, with less emphasis placed on control, and choice articulated as the dominant factor. Across the extracts,

choice was referenced more frequently than control,¹⁸ and control was not discussed in any extract in which choice did not also appear.¹⁹ On one occasion, in which a document cited Scottish legislation, control was expressed as deriving from choice:

A further element of independent living – control – is reflected in the provisions of the Act enshrining choice...(and in individuals having as much involvement as they wish in relation to the assessment and provision of support or services).²⁰

In these texts, therefore, control was the subordinate idea to choice, which – in relation to control – also stood alone in the texts.

The Welsh texts also deployed the ‘mantra’ of ‘choice and control’.²¹ In one of these references the Arfon Access Group, expressed concern about the Welsh Government’s use of the similar phrase ‘voice and control’:

Many of us were dismayed to see the term 'choice' lost from the phrase 'choice and control' to be replaced by 'voice and control'. ... While voice is important we feel that choice is critical and it is important to bring it back into the Bill...²²

¹⁸ Including the citations of this definition, choice was referenced in 16 extracts across five documents, and control in nine extracts across four texts.

¹⁹ Of the references to control in the extracts, only one extract did not also mention choice. However, this extract occurred in a wider discussion in which choice was expressed.

²⁰ Disability Wales / Anabledd Cymru, on behalf of Partner Organisations, ‘Consultation response, Health and Social Care Committee Social Services and Well-being (Wales) Bill’ (March 2013) <<http://www.senedd.assembly.wales/documents/s15186/SSW%2015%20Partner%20Organisation%20co-ordinated%20by%20Disability%20Wales.pdf>> accessed 10 November 2016, 9, citing the Explanatory Note to the Scottish Executive Social Care (Self-Directed Support) Bill. Scottish Government, ‘Explanatory Notes: Social Care (Self-directed Support) (Scotland) Act 2013 (asp 1)’ (TSO 2013) <<file:///H:/PhD/Documents/Scotland%20SDS%20Act/Ex%20notes%20cited%20in%20DW%20document.pdf>> accessed 22 July 2019.

²¹ This phrase was specifically connected to independent living on three occasions in the dataset. Across the texts more widely, eleven further references to ‘choice and control’ were found, along with two similar phrases. These were, ‘freedom, choice, dignity, control and opportunities’ in Disability Wales, ‘Manifesto for Independent Living (n1) 6; and ‘choice, control and independence’ in Disability Wales on behalf of Partner Organisations (n20) 8.

²² Arfon Access Group (n8) 1.

'Voice' is a core element of the Welsh Government's communitarian narrative that is set out in Chapter 3, section 5. Voice was included in certain of the Welsh dataset texts, but only in relation to the matter of advocacy,²³ or – as in the above extract – where the Welsh Government agenda of 'voice and control' was under discussion.

As in the Anglo-British DPM dataset, in the Welsh extracts, choice and control were typically expressed in unqualified terms which typically implied non-compromised conditions. On various occasions this was reinforced by references to 'genuine choice and control',²⁴ or by references to equality:

Independent living remains an effective framework for understanding and tackling the barriers that disabled people face which prevent them from having the same choices, opportunities and control of their lives as non-disabled people.²⁵

This extract echoes those in the Anglo-British DPM dataset which also emphasised the matter of disabled and non-disabled people having the *same* choice and control. However, in certain extracts the ideas of choice and control were compromised:

We believe that similar legislation in Wales would *maximise* citizens' choice and control over the support they receive and would establish a basis for the transformation of Social Services that WG envisage (emphasis added).²⁶

²³ For example: 'Advocacy Wales, the national umbrella organisation for Independent Advocacy providers, calls for "the expansion of Independent Advocacy for adults across Wales as a vital service which enables citizens to make their voice heard, secure their rights and access the support they need to live the life they choose."' Disability Wales, 'Manifesto for Independent Living' (n1) 7; 'All Wales People First is the United Voice of Self – Advocacy Groups and all People with Learning Disabilities in Wales.' All Wales People First, 'Manifesto 2016' (2016) <<http://allwalespeople1st.co.uk/resources/manifesto-2016/>> accessed 2 January 2017, 2.

²⁴ Disability Wales, 'Manifesto for Independent Living' (n1) 5 and 11.

²⁵ Disability Wales / Anabledd Cymru, 'Written Evidence Submitted to the Joint Committee on Human Rights (IL 39)' (27 April 2011). Published in, Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (2011) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019, 164-169, 166.

²⁶ Disability Wales on behalf of Partner Organisations (n20) 11, in the discussion on Scottish legislation. See also the extract cited above which is also part of this discussion.

Choice and control were important themes in the dataset documents beyond the extracts that directly cited independent living.²⁷ Again, on some occasions, where public sector support was under discussion they were expressed as compromised ideas:

‘Many disabled people want more choice and control over their lives and a more personalised and participative approach to service provision’.²⁸

However, the need for a shift of control and power from state agencies to disabled people was emphasised:

[Disability Wales] would like to see the transfer of control to disabled people extended further through implementation of [citizen-directed support].²⁹

4.2. Social agency

The narrative of independent living as an active life in the community was also found in the Welsh extracts. The broad idea of an active fulfilled life was expressed in the short ‘definition’ of independent living which – as discussed above – established independent living as the means by which disabled people could:

achieve our own goals and live our own lives in the way that we choose for ourselves.

This definition conveyed a sense of life opportunity, although the stronger focus was on personal agency.

²⁷ Across the texts there were 63 sections in which choice was discussed, and 43 which considered control, including the extracts in which independent living was referenced.

²⁸ Disability Wales, ‘Manifesto for Independent Living (n1) 3.

²⁹ Disability Wales, ‘Written Evidence’ (n25) 165.

The most detailed and strongest exposition of the narrative of social agency in the extracts was in the longer explanation of independent living in the Disability Wales Independent Living Manifesto:

Ensuring that disabled people have the same freedom, choice, dignity, control and opportunities as any other citizen – at home, at work and in the community.³⁰

This extract expressed the ideas of citizenship and the holding of social roles as a ‘natural’ or expected state for disabled people, although it lacked the detail that was found in certain of the Anglo-British DPM dataset documents.³¹ As with the extracts from that dataset that expressed social agency, it strongly conveyed the notion of equality. These extracts implicitly and explicitly expressed the importance of access in having an active social life as members of the community.

When the texts were examined more widely it was found that the narrative of social agency was present, albeit expressed in relatively brief passages. Certain passages – particularly in the All Wales People First Manifesto – indicated that even modest forms of social – and indeed personal – agency were still unavailable:

There are rotas for the TV, friends or partners cannot be brought home. And going out to meet up with friends has to be arranged.³²

4.3. Equality and rights

Rights were strongly connected to independent living in the Welsh texts.³³ In the extracts that related independent living to rights, the majority referred to independent

³⁰ Disability Wales, ‘Manifesto for Independent Living (n1) 6.

³¹ As discussed in Chapter 6, section 3 and footnote 15 above, this lack of detail was also generally true of the later documents in the Anglo-British DPM dataset.

³² All Wales People First (n23) 9.

³³ In the extracts there were 15 references to rights, occurring within three documents only - the Disability Wales ‘Manifesto for Independent Living’ (n1), the Disability Wales response on behalf of Partner Organisations (n20) and the Disability Wales written evidence to the Joint Committee of Human Rights (n25).

living as a right, often with reference to Article 19.³⁴ Other extracts referred to specific aspects of independent living as rights³⁵ or to the dependence of independent living upon other rights and entitlements.³⁶

In the texts more widely, there were multiple references to rights in various forms. The All Wales People First manifesto expressed a number of specific matters as rights, such as ‘speaking up’, safety and the expression of sexual identity. The Disability Wales Partner Organisations response document also made references to the right to take risks in one’s own life.³⁷ However, general references to *equal* rights, while present, were scarce.

This lack of emphasis on equality was echoed in the discussion of independent living. As noted in section 3 above, an explicit statement of equality was absent from the Disability Wales short definition of independent living. Across the dataset as a whole, independent living was connected to the idea of equality eight times, three of which occurred within the longer definition of independent living in the Disability Wales Manifesto discussed above. However, in the wider texts equality was frequently referenced,³⁸ and was central. For example, it was expressed as a core priority for Disability Wales:

[Disability Wales] is the national association of disabled people’s organisations, striving to achieve equality, rights and independence for all

³⁴ Of the 15 references to rights in the extracts, 12 referred to independent living as a right. In one of these the connection was made by the parliamentary Joint Committee on Human Rights, to which Disability Wales was providing evidence. In another independent living was impliedly framed as a right. ‘Whilst the SSW Bill, as introduced, includes a welcome focus on achieving well-being outcomes, it fails to include Independent Living in the definition of well-being. This lack of a rights based focus is particularly surprising...’. Disability Wales on behalf of Partner Organisations (n20) 6.

³⁵ Dignity and the ‘right to participate in community life’. Disability Wales on behalf of Partner Organisations (n20) 11. This reference occurred in the governmental discussion of independent living in Scotland cited in that response.

³⁶ For example: ‘DW supports the statement by Independent Living in Scotland (ILiS) that: “For independent living to be a reality, disabled people need access to certain basic rights. Self Directed Support (SDS) is one of these rights. For some disabled people it is an essential link in the chain of rights needed to ensure they are free to live their life in the way they choose, to be in control of it and to do this with dignity’. Disability Wales, ‘Written Evidence’ (n25) 166.

³⁷ For example: ‘... recommend an amendment to the SSW Bill to acknowledge the right of individuals to take risks... and to ensure that risk is managed on an individual basis’. Disability Wales on behalf of Partner Organisations (n20) 17.

³⁸ There were 33 sections in which equality was mentioned or discussed.

disabled people....³⁹

Similarly, the Disability Wales 2016 Manifesto looked to:

an Enabling Wales where disabled people truly experience their rights and equality as citizens of a modern inclusive nation, contributing fully to its social and economic success.⁴⁰

4.4. Enablers of independent living

By far the most striking difference in the narrative of independent living between the Welsh and Anglo-British texts occurred in discussion of how it should be enabled. There were certain similarities. As in the Anglo-British DPM dataset, access was a critical enabler and was strongly emphasised.⁴¹ There was also reference to the importance of self-directed support:

The Disability Wales evidence to Joint Committee on Human Rights also cited a right to self-directed support as a requirement for independent living, citing the work of the organisation Independent Living in Scotland.⁴²

However, direct payments and personal assistance were almost never explicitly connected to independent living, although they were discussed in the texts more widely. Direct payments were directly connected to independent living twice and personal assistance only once. Both were set out as one of a number of options. The Arfon Access Group, for example, stated:

³⁹ Disability Wales, 'Manifesto for Independent Living' (n1) 2.

⁴⁰ Disability Wales / Anabledd Cymru, 'Disabled People's Manifesto' (2016) <<http://www.disabilitywales.org/wordpress/wp-content/uploads/DW-Manifesto-BILINGUAL-FINAL.pdf>> accessed 9 November 2016, pages unnumbered. This document also included a statement that powers over equality legislation should be devolved to the Welsh Government.

⁴¹ Where independent living was expressly referenced, access (together with individualised support) was the most commonly cited enabler, with eight references. In the documents more widely, access was the most commonly cited enabler, with 28 references.

⁴² Disability Wales, 'Manifesto for Independent Living' (n1) 7.

In order to achieve Independent Living the mechanisms of support need to meet individual requirements, whether through Direct Services, Agency Staff, co-productive arrangements or directly employed Personal Assistants under a Direct Payments scheme.⁴³

This contrasted with the Anglo-British DPM dataset, in which these mechanisms were seen as fundamental to, and sometimes almost synonymous with, independent living.

As stated above, both direct payments and personal assistance were omitted from the six 'calls to action', or priorities for independent living, articulated in the Disability Wales Manifesto for Independent Living. The section in the Manifesto that related to social care contained discussion of direct payments, but did not refer to personal assistance.

When the documents were considered more widely, it was found that there were no references to personal assistance in either of the Disability Wales Manifestos or the Disability Wales response to the Joint Committee. A handful of references appeared in the Partner Organisations' response to the Social Services and Well-being (Wales) Bill, with one expressed ambivalently.

We recognise that whilst the lives of many individuals have been transformed through Direct Payments ... some people will not wish to have the responsibility of directly employing their own Personal Assistant.⁴⁴

Direct payments were more frequently discussed but were not given the unambiguous support found in the Anglo-British texts. Discussion of the 'call to action' relating to support in the Disability Wales Manifesto for Independent Living contained two 'priority actions' relating to the wider take up of direct payments,⁴⁵ but

⁴³ Arfon Access Group (n8) 3. See also, 'The Welsh Assembly, which adopted the Social Model of Disability in 2002, is already engaged in work that supports Independent Living, e.g. the commitment to Direct Payments, the development of community equipment stores and the priority given to making rail travel accessible'. Disability Wales, 'Manifesto for Independent Living' (n1) 4.

⁴⁴ Disability Wales on behalf of Partner Organisations (n20) 11-12.

⁴⁵ Disability Wales, 'Manifesto for Independent Living' (n1) 11-12.

also two references to direct payments that were relatively equivocal. One of these was a quote from a parent of a disabled child stating that she would have preferred the English model of ‘individualised budgets’ rather than direct payments.⁴⁶ The other stated that direct payments were not essential to obtaining control over support.⁴⁷ In contrast, the Partner Organisations’ consultation response placed very significant focus on direct payments, positioning them as a critical means of support. This document both suggested that the existing requirement to ‘opt-in’ to direct payments, should be altered to an ‘opt-out’ system;⁴⁸ and suggested ways in which direct payments could be used to further ‘collective approaches to support provision’, including cooperatives and pooling payments.⁴⁹

Partially as a result of this lesser focus on direct payments and personal assistance, the idea of ‘services’ was more prominent in the Welsh DPM documents than in the Anglo-British DPM dataset. In the latter, discussion of ‘services’ was effectively replaced with the idea of personal assistance funded by direct payments. In the Welsh texts, an acceptance of ‘services’ remained, both in the extracts and in the texts more widely. Indeed, the notion of ‘traditional services’ was on occasion explicitly incorporated into the discussion – as seen in certain of the extracts cited

⁴⁶ Ibid 12. It was not clear what distinction between an ‘individualised budget’ and a direct payment was considered of importance here. The full statement read: ‘Sonny was the first child in Wales to have a direct payment, and then when he embarked upon adult life what I really wanted was an individualised budget, but I guess the direct payment is in a sense that. Sonny does have Independent Living Funds alongside the direct payment, but I think I would feel safer long term for him if it was an individualised budget, and we were following the model that exists in England.’ A direct payment is effectively the amount of an ‘individualised budget’ provided in cash (a matter that has been formalised in the Care Act 2014). As the parent did not state why an ‘individualised budget’ would be safer than a direct payment, or this section was not quoted, this remained unclarified.

⁴⁷ Disability Wales, ‘Manifesto for Independent Living’ (n1) 11. This reference comprised an extract quoted from, Independent Commission on Social Services in Wales, ‘From Vision to Action’ (2010) <<https://www.valeofglamorgan.gov.uk/Documents/Our%20Council/Achieving%20our%20vision/Independent-Commission-on-Social-Services,-November-2010.pdf>> accessed 29 July 2019.

⁴⁸ The document referenced a Member’s Bill brought before the National Assembly for Wales and withdrawn on 6 February 2013. The Community Care (Direct Payments) (Wales) Bill was brought by Mark Isherwood AM working in discussion and cooperation with Disability Wales. Had the bill progressed, it would have introduced an opt-out system for direct payments in Wales. For information on the Bill see, National Assembly for Wales, ‘Bill-021 - Mark Isherwood - Community Care (Direct Payments) (Wales) Bill’ (undated) <https://www.assembly.wales/en/bus-home/archive-business/bus-fourth-assembly/bill_ballots/Pages/bill_021.aspx> accessed 19 July 2019 and National Assembly for Wales, ‘Development of the Community Care (Direct Payments) (Wales) Bill’ (undated) <https://www.assembly.wales/en/bus-home/archive-business/bus-fourth-assembly/proposed_members_bills/Pages/community_care__direct_payments__wales__bill.aspx> accessed 19 July 2019.

⁴⁹ Disability Wales on behalf of Partner Organisations (n20) 8-12.

above and the discussion of citizen-directed support immediately below. A potential difficulty in the texts here was the lack of detailed discussion as to how ‘services’ might enable the core elements of personal and social agency, opening up a ‘gap’ in the counter-narrative in Wales.

Another clear distinction between the Anglo-British and Welsh DPM dataset texts was the connection in the latter of independent living and citizen-directed support (CDS). CDS was a proposed framework for social care provision, specific to Wales, which was developed co-productively by ‘citizens and service recipients, local authorities and service providers’,⁵⁰ including disabled people.⁵¹ Working in particular through the network of the Wales Alliance for Citizen Directed Support (WACDS), agencies built upon the principles of self-directed support⁵² that had been developed in the English context, and which had itself borrowed ideas from the principles of independent living.⁵³ CDS promoted control for those accessing support and a transparent allocation of funding. The feature that distinguished CDS from self-

⁵⁰ Ibid 7.

⁵¹ Wales Alliance for Citizen Directed Support (WACDS), ‘Effective Services for Vulnerable Groups: Citizen Directed Support: Full Report’ (undated) <https://www.wcva.org.uk/media/394387/esvg_-_cds_-_final_report.pdf> accessed 22 July 2019, 3.1.

⁵² Ibid. See, ‘The term Citizen Directed Support is used specifically and purposely in Wales, as Wales develops its own approach. In England as part of Self Directed Support, the term “personalisation” is used and in Scotland “Self Directed Support” is used.’ Para 3.2. See also Simon Duffy, ‘What is Citizen-Directed Support?’ (*Centre for Welfare Reform*, 2012) <<http://www.centreforwelfarereform.org/library/by-az/what-is-citizen-directed-support.html>> accessed 1 June 2018.

⁵³ The term ‘self-directed support’ (SDS) is sometimes, and historically, used – particularly by disabled activists – to refer simply to the principle that individuals should be in charge of their own daily living assistance. For example, Stuart Bracking, ‘A Socially Based Approach to Self-Assessment’ (BCODP seminar, ‘Making Our Own Choices’ (1992) <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 18 November 2016. However, in England it has more recently been linked to the personalisation agenda and particularly the mechanism of personal budgets. Pearson, for example, refers to ‘[I]ndividual budgets (also known as self-directed support)’. Charlotte Pearson, ‘Independent Living’ in Nick Watson, Alan Roulstone and Carol Thomas (eds), *Routledge Handbook of Disability Studies* (Routledge 2012), 220. In this context, SDS has been developed by people and organisations external to the disabled people’s movement, including non-DPO charities. A seven-stage model of SDS, specifically connected to the mechanism of personal budgets, was devised and promoted by Simon Duffy in 2000, although this was later adapted to remove the reliance on personal budgets. Simon Duffy, ‘Self-Directed Support’ (*Centre for Welfare Reform*, 2010) <<http://www.centreforwelfarereform.org/library/by-az/selfdirected-support.html>> accessed 1 June 2018. Morris notes the conflation within the term SDS of the principle of being in charge of one’s own assistance and the mechanisms for achieving this. Jenny Morris, ‘Personal Budgets and Self-Determination’ (blogpost, 24 April 2014) <<https://jennymorrisnet.blogspot.com/2014/04/personal-budgets-and-self-determination.html>> accessed 8 May 2014.

directed support was an emphasis on mutuality and collectivism – in addition to enabling support for individuals, CDS was intended to develop the wider community and to counter the commodification and commercialisation of services.⁵⁴

CDS was presented as a specifically Welsh enabler of independent living:

‘[WACDS] ... has worked co-productively since 2008 to develop a new model of Social Services that is appropriate to the Welsh context.... The Welsh model of Citizen Directed Support is envisaged as a set of nationally agreed values, principles and practices which support innovation, enhance wellbeing, enable Independent Living and support citizens to achieve their chosen goals and lifestyles.’⁵⁵

It was also articulated as an essential requirement:

To this end, [Disability Wales] maintains that CDS should not be taken forward in isolation from wider policy development but as an integral part of a National Delivery Strategy on Independent Living in Wales.⁵⁶

In the documents more widely, CDS was a central and repeated theme that was accorded high levels of discussion,⁵⁷ and was closely connected to aspects of independent living. It was implicitly associated with the social model of disability,⁵⁸ and stated to be based on the principles of ‘choice and control, change and community’.⁵⁹ As indicated in an excerpt also cited above, CDS was envisaged as a means of shifting control from state agencies or professionals to individuals:

⁵⁴ WACDS (n51) para 3.2.

⁵⁵ Disability Wales on behalf of Partner Organisations (n20) 7.

⁵⁶ Disability Wales, ‘Written Evidence’ (n25) 166.

⁵⁷ CDS also remained connected to independent living although this phrase was not repeatedly used. The Disability Wales Written Evidence to the Joint Committee (n25), which is concerned explicitly with independent living in the Welsh context, contains a strong emphasis on CDS.

⁵⁸ ‘....by focusing on identifying and removing the barriers that prevent disabled and older citizens from actively participating in their communities...’. Disability Wales on behalf of Partner Organisations (n20) 7.

⁵⁹ Disability Wales, ‘Written Evidence’ (n25) 165.

...[Disability Wales] would like to see the transfer of control to disabled people extended further through implementation of CDS.⁶⁰

Direct payments and the English mechanism of personal budgets were important elements of CDS.⁶¹ However, CDS was also connected to established forms of support delivery:

The model supports local innovation and provision of a range of options for *service users*, including Direct Payments and *traditional service delivery* for those who want it. (Emphases added.)⁶²

Collective or community approaches to social care support that were associated with CDS included 'building social capital and community development',⁶³ shared lives schemes,⁶⁴ timebanking,⁶⁵ and cooperatives.⁶⁶ However, despite the enthusiasm in the texts for CDS, and apparent similar enthusiasm from the Welsh Government,⁶⁷ Arfon Access Group (AAG) articulated a concern that 'an apparently firm commitment to CDS' on the part of the Welsh Government was giving way to the

⁶⁰ Ibid 165.

⁶¹ WACDS (n51). In an undated document formerly available on its website, Disability Wales described CDS as, '... a further extension of direct payments which aims to shift power and control over services directly to disabled people. Following supported self-assessment, planning and resource allocation, individuals are given control of an individual budget which can be used in the form of a direct payment, as direct service provision, or as a mixture of both. After negotiation and agreement between the individual and professionals, the budget can be used in appropriate and creative ways to achieve agreed outcomes' Disability Wales, 'Direct Payments & Citizen Directed Support' (undated) <<http://www.disabilitywales.org/social-model/independent-living/direct-payments-citizen-directed-support/>> accessed 9 March 2018.

⁶² Disability Wales, 'Written Evidence' (n25) 165.

⁶³ Ibid 165.

⁶⁴ In these schemes an individual lives with a host family and receives support from them while sharing their family life. WACDS (n51).

⁶⁵ Timebanking is a means by which people can undertake work and be 'paid' in credits which can be exchanged for work done for them in return or to undertake other activities. See Timebanking UK, 'What is Timebanking?' (undated) <<https://www.timebanking.org/what-is-timebanking/>> accessed 22 July 2019.

⁶⁶ Disability Wales on behalf of Partner Organisations (n20).

⁶⁷ Arfon Access Group (n8). In April 2013, the Chair of the Welsh Government programme 'Effective Services for Vulnerable Groups' endorsed a report on CDS and suggested that the CDS approach was to be 'mainstreamed' within social services. Letter from Dr. Andrew Goodall, Chief Executive, Aneurin Bevan Health Board and Chair, Effective Services for Vulnerable Groups Programme, Public Service Leadership Group to various (17 April 2013) <<https://www.c3sc.org.uk/partnerships/partnerships-doc-lib/what-matters/370-effective-services-for-vulnerable-groups-citizen-directed-support-cover-letter/file>> accessed 29 July 2019. The report referred to appeared to be that cited at note 51, above.

less radical idea of ‘citizen-centred’ support.⁶⁸ It is certainly the case that since the authorship of these documents, the focus of the Welsh Government on CDS has dissipated.⁶⁹

A further core distinction between the enablers in the Welsh texts and the Anglo-British DPM dataset was the focus on ‘personalisation’ that was included in the priorities and sections of the Disability Wales *Manifesto* that focused on social care. Personalisation is outlined in Chapter 3, Section 6.1. It has become the central element of adult social care policy in Westminster. Broadly speaking it refers to the idea of support being tailored to the individual recipient and is connected in England with the delivery mechanisms of direct payments and personal budgets.

Personalisation was discussed in positive terms in some of the Welsh texts. For example:

The forthcoming White Paper on the future of social care in Wales must heed this recommendation and include an action plan to drive the personalisation agenda forward. This is essential if disabled people in Wales are to enjoy choice and control over the services they need to achieve Independent Living.⁷⁰

Certain of the texts also embraced the idea of personal budgets,⁷¹ with one extract expressing a desire for ‘the model that exists in England’ rather than direct payments.⁷² In contrast, in the Anglo-British DPM dataset, ‘personalisation’ and personal budgets were seen as government initiatives.⁷³ While certain of the later

⁶⁸ Arfon Access Group (n8) 2.

⁶⁹ In recent years, the language of ‘CDS’ has disappeared from Welsh Government policy, and pages on the Welsh Government website that formerly referred to CDS have been removed. Similarly, references to CDS in Welsh Government documents have not been followed up. See Chapters 10 and 11.

⁷⁰ Disability Wales, ‘Manifesto for Independent Living’ (n1) 11. See also: ‘Provision of personalised, outcome focused social care and support services is vital to achieving Independent Living for many disabled people in Wales’. Disability Wales, ‘Written Evidence’ (n25) 165. Note also the connection of CDS to personal budgets noted above and in note 61.

⁷¹ For example, Disability Wales, ‘Manifesto on Independent Living’ (n1) 11 and 12.

⁷² Ibid 12. See discussion in this section above and footnote 46.

⁷³ For example, Peter Beresford, *What Future for Care?* (Joseph Rowntree Foundation 2008); Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011); Inclusion London, ‘Evidence of Breaches of Disabled People’s Rights under the UN Convention on the Rights of Persons with Disabilities’ (2015) <<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and->

documents referred to personalisation and indicated agreement with ideas connected with it, the language of personalisation was not adopted to express the ideas or requirements of the disabled people's movement.⁷⁴ Indeed, Morris (citing Beresford) argued that personalisation was distinct from independent living.⁷⁵ There was therefore in Wales an embracing of a *governmental* initiative to support independent living, although in Wales this amounted to a challenge to the principles of the Welsh Government, which has rejected personalisation.⁷⁶

As with the texts in the Anglo-British DPM dataset, there was significant discussion of various forms of co-production, although this tended not to be connected directly to independent living. Co-production was seen as the essential way forward for social care services:

The partner organisations call upon the Committee to seek an assurance from [the Welsh Government] that the Code of Practice will establish Co-production as the preferred method of delivering a genuinely transformed Social Services across Wales.⁷⁷

Co-production was expressed as a core element of CDS.⁷⁸ The Partner Organisation response argued that the guidance under the (then) forthcoming social care legislation should '[support] development of a co-produced model of Citizen Directed Support'.⁷⁹ Co-production was envisaged at an individual level, through a 'participative approach to service provision' and, by the Arfon Access Group, as

information/equality-and-human-rights/evidence-of-breaches-of-disabled-peoples-rights-under-the-un-convention-on-the-rights-of-persons-with-disabilities/> accessed 2 January 2017.

⁷⁴ There was one exception. Inclusion London made a 'priority demand' for 'increasing quality and range of personalised support available to disabled people' in relation to employment. Inclusion London, 2013, 12.

⁷⁵ Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation, 2011), 12, citing Peter Beresford, 'Whose Personalisation?' (Compass 2009). As these references demonstrate, in the English context, the disabled people's movement has a complex relationship with personalisation. While certain aspects have generally been welcomed, it has also been criticised as a governmental concept that appears to mimic ideas and language from the disabled people's movement – particularly those connected with independent living – while pertaining to a wider governmental agenda of public sector marketisation.

⁷⁶ See Chapter 3, section 6.1.

⁷⁷ Disability Wales on behalf of Partner Organisations (n20) 3 and 22.

⁷⁸ As noted above, CDS was stated to have been developed by 'citizens and service recipients, local authorities and service providers'. Ibid 7.

⁷⁹ Ibid 2 and 8.

direct payments;⁸⁰ and at a policy and strategic level. In terms of the latter, Disability Wales envisaged co-production as a requirement for a shift in narrative:

To counteract devaluing attitudes, prejudice, disablism and discrimination, disabled people must be actively involved and engaged in all planning, design and commissioning processes.⁸¹

5. Discussion

In essence, independent living held the same values in the Welsh and Anglo-British documents. In the Welsh texts, as in those from the Anglo-British DPM dataset, independent living expressed the capability and the right of disabled people to enjoy self-determination and an active, social community life on an equal basis with others. However, there were also certain different emphases in the Welsh context. The findings here must be considered in the light of the fact that the movement in Wales shared the roots of independent living with the Anglo-British movement, that there were few Welsh documents available for study and that the authorship of those documents was narrower than in the Anglo-British context.⁸²

The strong focus on the narrative of personal agency in the Welsh documents demonstrated a clear belief in the right and scope of disabled people to self-determine, and to live life on their own terms. It was this aspect that was very specifically encapsulated in the short 'definition' of independent living coined by Disability Wales. The potential risk to this narrative was indicated in the extract expressing concern that in Welsh Government texts the idea of choice was giving way to that of 'voice'. It is noted in Chapter 3, section 5 that 'voice' is a central principle of the Welsh Government communitarian narrative, where it is explicitly designed to repudiate individual choice. The concern raised in this text indicated both the importance of choice to independent living activists in Wales, and that this

⁸⁰ Arfon Access Group (n8) 3.

⁸¹ Disability Wales, 'Manifesto for Independent Living' (n1) 18.

⁸² In addition, two of the six documents studied were responses to the Welsh Government's consultation on forthcoming social care legislation, and were therefore responding to the government agenda.

essential fragment of personal agency was at risk in the Welsh context.

Despite this, the Welsh texts indicated a certain modification of the individualism found in the Anglo-British DPM dataset. The emphasis on choice rather than control in the Welsh texts may have been a conscious or unconscious response to the threat to choice in Wales. However, it also suggested that there might be less interest among activists in Wales in reconceptualising the relationship between disabled people and supporting structures in the way that was apparent in the early Anglo-British texts. A desire for a shift of control to disabled people was certainly articulated, but the enabling mechanisms that were considered in the Welsh texts suggested that this might be sought in a way that utilised rather than rejected existing state structures and mechanisms. The stronger focus on choice, which does not *necessitate* a separation between the individual and the public sector, also suggested that there might be space in Wales for an exploration of how self-determination and independent living might be animated and enabled through democratic and participatory structures and processes rather than individualised forms of assistance.

This was reinforced by the discussion of direct payments as one of a number of means of receiving support rather than a pre-requisite for independent living, and the retention of a focus on ‘traditional services’, which indicated an interest in working alongside state structures and services rather than replacing or re-developing them. This apparent approval of existing forms of support and the decision not to question the language of ‘services’ was diametrically opposed to the message in the Anglo-British DPM dataset that independent living grew out of resistance to such approaches and their underlying narratives. It created a general sense in the Welsh texts of a less radical approach than was found in the Anglo-British texts. Overall, the Welsh texts indicated an apparent willingness to work *within* the remit of existing public service delivery rather than to reject it. While narratives around disabled people were challenged, there was perhaps less willingness to question fundamental principles of the existing welfare state – principles which, it should be remembered, stemmed partially from the Welsh social history and political tradition.⁸³

⁸³ See Chapter 3, section 5.

The lesser focus on direct payments and the almost complete absence of discussion of personal assistance, also suggested that this highly individualistic form of support had not yet put down strong roots in the Welsh context.⁸⁴ In contrast, the discussion of community and cooperative approaches, including through the use of direct payments, indicated a clear interest in approaches to support that drew on ideas of mutuality and collective responsibility, and in re-developing elements such as direct payments in a way that engaged with communitarian approaches to state provision. This pull towards more communitarian approaches was also seen in the inclusion of references to the social model of disability in the longer definition of independent living set out in the *Disability Wales Manifesto*. Overall, the documents had a strong emphasis on the social model of disability, which was clearly considered to be of particular importance, both in general and in relation to independent living.⁸⁵

One aspect that was very clear, however, was that the disabled people's movement in Wales, like its Anglo-British counterpart, was emphasising ideas that resonated in the particular political context. While the texts in the Anglo-British DPM dataset had emphasised the individualistic aspects of independent living, the Welsh texts drew heavily on the ideas and principles of communitarianism that were prevalent in the Welsh Government narrative. As in the Anglo-British DPM dataset, however, certain critical elements remained largely undiscussed. Most notably in the Welsh texts, while co-production was emphasised, there was very limited exploration of precisely *how* the individualism inherent in independent living – and clearly prized in Wales – could be animated through more collectivist structures. This left gaps and potential problems in the counter-narrative which might give scope for confusion or omission when independent living was transposed into the policy arena.

⁸⁴ Exploration of this apparent lack of enthusiasm was outside the scope of this thesis. Potential reasons might have included a lack of interest on the part of disabled people and others using social care support, the distaste for individualistic approaches on the part of the Welsh Government, the difficulties in enabling personal assistance in areas with very few large urban units and large rural populations, or the historically low take up of direct payments in Wales and the lack of CILs and similar forms of peer support.

⁸⁵ This point is reinforced by a statement of 'core values' on the Disability Wales website, which cites as core values, the social model of disability; equality, diversity and human rights; an inclusive society; self-determination; beacon of best practice; and 'committed to achieving quality', but which makes no explicit reference to independent living. See, Disability Wales, 'Core Values' (undated) <<http://www.disabilitywales.org/about/core-values/>> accessed 19 July 2019.

6. Conclusion

It was clear in the Welsh texts that disabled activists in Wales felt strong affiliation with the counter-narrative of independent living and the fundamental fragments as established in the Anglo-British movement, but also wished to emphasise and develop certain aspects. This may have been partly in response to the Welsh political context and the need for activists in Wales to find their own points of adjacency with a Government that held to a very different political discourse from that in Westminster, and to mitigate areas of potential collision. The following chapter sets out these areas of adjacency and collision, and highlights matters arising from the use of the language of independence in the independent living counter-narrative. That chapter concludes this part of the thesis and sets the groundwork for the examination of independent living in the policy and legislative texts in Wales.

Chapter 8: Narrative relationships: adjacency and collision; countering and compliance

1. Introduction

This chapter looks ahead to the discussion of independent living in the Welsh policy and legislative texts. It draws on the findings from the analysis of the Anglo-British and Welsh DPM texts to set out broad areas of adjacency and collision between independent living and the principles of the Welsh Government communitarian narrative introduced in Chapter 3. The chapter then introduces an area in which a struggle for meaning between the disabled people's movement and the Welsh Government is particularly likely – the use of the language of independence – and demonstrates how concerns about such a struggle for meaning were heralded by 'dissenters' within the disabled people's movement. This discussion prepares the ground for the examination of the fragments and language of independent living in policy and legal texts in Wales, and the impact on the counter-narrative of its incorporation into these texts.

2. Adjacency and collision between independent living and the Welsh Government communitarian narrative

Counter-narrative theorists have identified that there are complex relationships between counter-narratives and the master narratives that they resist, and that there may be tension in a counter-narrative between countering and complying with a

master narrative.¹ It is argued in this thesis that this theoretical discussion needs to be extended to enable the analysis of the relationships between counter-narratives and policy. A framework of 'adjacency and collision' was proposed to enable this analysis. 'Adjacent' relationships are those in which the same or similar language and ideas occur, creating an appearance of a consensus which may or may not exist. 'Colliding' relationships occur where there is, or appears to be, opposition between fragments of the counter- and the policy narrative. Such collision may be partial or total and must be remedied or obscured if a counter-narrative is to be incorporated effectively into policy.

The examination of fragments of independent living in Chapter 6 demonstrates that independent living holds strong inclinations towards individualism. The adjacency of individualism – and the persona of the self-determined and self-responsible citizen – to both independent living and the neoliberal ideology emerging as a new orthodoxy in Westminster is touched upon in the discussion in Chapter 6 on direct payments. Discussion of the impact of this adjacency is well-rehearsed elsewhere and is outside the scope of this thesis.² It is worth noting here, however, that this adjacency between independent living and Westminster policy narratives may have enabled a certain form of independent living to thrive within the movement, with aspects relating to personal agency foregrounded relative to other fragments. In *Wales*, relationships of adjacency and collision between independent living and government narratives would be entirely different from those in the Anglo-British context. The discussion of Welsh political discourse in Chapter 3 demonstrates that this departs from many of the principles championed in Westminster and is imbued with the

¹ Chapter 4, section 7.

² Morris's suggestion that independent living has been 'colonised and corrupted' is noted in Chapter 6, section 4.4.1. Similarly, Oliver has stated that the ideas of the disabled people's movement have been 'distorted'. Michael Oliver, 'Welfare and the Wisdom of the Past' (*Disability Now*, February 2013) <<http://www.disabilitynow.org.uk/article/welfare-and-wisdom-past>> accessed 19 August 2013. Pearson and Sapey have highlighted the connections between independent living and individualist narratives. B Sapey and J Pearson, 'Do Disabled People Need Social Workers?' (2004) 11(3) *Social Work and Social Sciences Review*, 52, cited in Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011). Roulstone and Morgan have suggested that disabled people are at risk of being moved from an 'enforced collectivism' to an 'enforced individualism'. Alan Roulstone and Hannah Morgan, 'Neo-Liberal Individualism or Self-Directed Support: Are We All Speaking the Same Language on Modernising Adult Social Care?' (2009) 8(3) *Social Policy and Society*, 333, 334. These are just a few of very many academic and activist texts that explore the impact of this broad adjacency between the disabled people's movement and Westminster policy, particularly in relation to direct payments.

principles of communitarianism and collectivism that are part of the Welsh socio-political heritage. This section considers the findings set out so far and proposes areas in which either adjacency or collision exist between independent living and the principles embedded in the Welsh Government communitarian narrative.

2.1. Relationships of collision

The focus on individualism in independent living is a necessary part of the counter-narrative. Independent living was developed to counter the problems of 'batch' living and external, imposed control. In the UK independent living began, historically and intellectually, with the process of disabled people – in genuinely courageous works of collective and individual activism – '[moving] out into the community *one by one*'³ to live their own self-defined lives. Personal agency, and its central components of choice and control, are integral to independent living and deemed to be definitional, and were strongly emphasised in both the Anglo-British and Welsh DPM texts. Regardless of its focus on ideas that incline towards a community existence and collective responsibility, including equality, social access, inclusion, participation and mutual support, independent living was *necessarily* conceived as a narrative to foreground the needs and desires of the individual and enable each person to live on their own terms. Indeed, it is noted in Chapter 2 that the explicit foregrounding of the individual is one of the core distinctions between independent living and the social model of disability.⁴

This focus on individualism tapped into narratives that had been rejected by activists within the early disabled people's movement. The discussion in Chapter 2, section 3 demonstrates that the social model of disability itself had been developed explicitly to refute the model of disability that Oliver had identified as highly problematic and

³ John Evans, 'The Role of Centres of Independent/Integrated Living and Networks of Disabled People' (paper at BCODP seminar, 'Making Our Own Choices', August 1992) <<https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019, 61, emphasis added.

⁴ Section 5.

arising from an 'ideology of individualism'.⁵ However, the individualism of independent living also provided a counterpoint to the collectivism inherent in the social model of disability, which formed the foundational counter-narrative of the movement. Within the social model, the liberation of the individual emanated from the collectivist solutions of access and integration. Independent living began with the individual and developed collective action from that – becoming the organising principle of an international movement. These two counter-narratives were therefore in a complementary relationship, with one providing a focus on changes necessary at the communal level and the other enabling each person to decide what was necessary for them as an individual.

Of these two activist counter-narratives, the social model, with its more collectivist focus, is a more natural 'fit' with the Welsh Government communitarian narrative. Indeed, it is notable that the social model was explicitly adopted by the Welsh Government as long ago as 2002.⁶ It is noted in the previous chapter that the texts by Disability Wales also had a strong focus on the social model. In Wales, the importance of the individual in independent living was an area of potentially fundamental collision between the counter-narrative and policy. The discussion of the Welsh Government communitarian narrative in Chapter 3 demonstrates a clear antipathy towards – or even a *rejection* of – individualism as a guiding principle of public sector policy. In his articulation of the underpinning principles of progressive universalism, Drakeford stated that, 'policy should be guided by the *collective voice* of civil society institutions rather than by *individual choice*' (emphases added).⁷ Similarly, the enablers of direct payments and personal assistance essentially collide with the statements that 'the delivery and receipt of public services should be a collaborative rather than a quasi-commercial transaction' and that 'government is the best vehicle for achieving social improvement'.⁸ Both direct payments and personal assistance are underpinned by the principle that the state is *not* the best vehicle for

⁵ Michael Oliver, *The Politics of Disablement* (Macmillan 1990), 46.

⁶ See Chapter 2, Section 3.

⁷ Mark Drakeford, 'Progressive Universalism', originally published in Institute of Welsh Affairs, 'Agenda' (Winter 2006-2007) and reproduced in, John Osbourne (ed), *Unpacking the Progressive Consensus* (Institute of Welsh Affairs 2008) <<https://www.iwa.wales/wp-content/uploads/2016/04/progconsensustext.pdf>> accessed 15 July 2019. See Chapter 3, section 5.

⁸ Ibid.

achieving improvement on an individual level,⁹ and the purpose of these models is specifically to remove the purchasing (or the provision) and management of support from the state. They also sit uneasily with the principle of universalism in services that is espoused in Wales. While there are multiple aspects of independent living that cleave to collective and communitarian ideas, this clear tension between policy principles in Wales and the essential thread of personal agency and the enabling mechanism of direct payments within independent living created difficulties for both the disabled people's movement and the Welsh Government if independent living was to be successfully incorporated into policy.

2.2. Relationships of adjacency

Other fragments of independent living are adjacent to principles that underpin the Welsh Government communitarian narrative. Broadly speaking, the narrative of social agency, with its focus on inclusion, participation and community living, was more obviously aligned to the principles of mutuality and collectivism prized in Wales and the principles of the Welsh Government communitarian narrative outlined by Drakeford. Other areas of obvious adjacency include equality and human rights, which form part of the legislative underpinnings of the governance institutions in Wales.¹⁰ 'Wellbeing' is a further concept that has been important in the Welsh policy and legislative context since the early days of devolution and which holds a level of

⁹ The Welsh Government 2004 *Direct Payments Guidance* makes the following statement. 'Day-to-day control of the money and care package passes to the person who has the strongest incentive to ensure that it is spent properly on the necessary services, and who is best placed to judge how to match available resources to needs' (para 10, emphasis added). Welsh Assembly Government, 'Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance Wales 2004' (2004) <<http://www.wales.nhs.uk/documents/direct-payment-policy-e-merge.pdf>> accessed 21 June 2019. This document was very heavily reliant on the equivalent 2003 document produced by the Department of Health for the English context (see, further, Chapter 9), and this statement is lifted directly from the Department of Health guidance. See Department of Health, 'Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance England 2003' (2003) <https://webarchive.nationalarchives.gov.uk/20071205205105/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4096246> accessed 22 July 2019.

¹⁰ See Chapter 3, Section 3.

adjacency with certain of the fragments of independent living identified in Chapter 6. A brief overview of each of these areas of adjacency is set out here.

Inclusion – or ‘inclusiveness’ – and participation have been central elements of a devolved Wales from the outset. Their importance is set out in Chapter 3, section 3, where it is indicated that one stated purpose for devolution was to develop a more inclusive and participative politics. Chaney and Fevre argue that ‘inclusiveness’ was a seminal idea both within the devolution campaign and in the early days of the Welsh institutions. They also contend that the meaning of ‘inclusiveness’ in this context shifted, and the concept expanded to encompass a wide variety of different ideas. In their words:

... the original term [of inclusiveness] was essentially an empty vessel into which a wide range of meanings and nuances were poured. It came to signify liberal concerns about fostering democratic participation, respecting pluralism, advancing equality, ending marginalization, reinventing a Welsh culture that is meaningful and embracing to all citizens, and developing a new mode of politics that is consensual and less adversarial.¹¹

In the modern Welsh political context, therefore, the notion of ‘inclusiveness’ – and by implication ‘inclusion’ – has a history of multiplicity of meaning that covers, but is by no means limited to, the ideas of social inclusion, integration and participation that were expressed in the narrative of social agency in independent living. Inclusion is also closely linked to equality in the Welsh policy context. Chaney suggests that the equality duty on the National Assembly for Wales ‘fitted neatly into the prevailing concept of “inclusiveness”’,¹² and Day notes that ‘[t]he main means for translating the political rhetoric of inclusion into reality was respect for the principle of equality of opportunity’.¹³ Chaney has also identified equality and social inclusion as two of

¹¹ Paul Chaney and Ralph Fevre, ‘Ron Davies and the Cult of “Inclusiveness”’: Devolution and Participation in Wales’ (2001) 14 *Contemporary Wales* 21, 31.

¹² Paul Chaney, ‘The Post-Devolution Equality Agenda: The Case of the Welsh Assembly’s Statutory Duty to Promote Equality of Opportunity’ (2004) 32(1) *Policy & Politics* 63, 65, citing Chaney and Fevre (n11).

¹³ Graham Day, ‘Chasing the Dragon? Devolution and the Ambiguities of Civil Society in Wales’ 2006 26(3) *Critical Social Policy* 642, 647.

three “cross-cutting” guiding themes’ of the Government of Wales Act 1998 (the other being sustainable development).¹⁴

The importance of equality in the Welsh Government’s policy and legislative framework is also discussed in Chapter 3, section 3. In summary, a uniquely comprehensive equality duty is enshrined as a legal principle for the Assembly in the devolution statutes of 1998 and 2006¹⁵ – a fact that places equality at the centre of the work of the Assembly and the Welsh Government. In Wales, strategy on independent living has always been connected with the Welsh Government’s equality duties. It is stated in Chapter 3, section 6.2 that the Welsh Government initially argued that independent living could be achieved through the provisions of the Equality Act 2010 rather than a separate strategy. When the 2013 *Framework for Action on Independent Living* was ultimately developed, it was directly linked to the Government’s 2012-2016 Strategic Equality Plan,¹⁶ and the Welsh Government Disability Equality Forum has a specific remit to advise on the implementation of the *Framework*.¹⁷

Requirements to uphold human rights are also worked into devolution legislation. Both the Assembly and the Welsh Government are required to uphold the European Convention on Human Rights – a matter that has led the Welsh Government to argue that human rights are ‘embedded ... in the very DNA of devolution itself’.¹⁸ In recent years rights have gained significant traction in Welsh Government discourse.

¹⁴ Paul Chaney, ‘New and Unexplored Possibilities – the Welsh Legislature’s Statutory Duty to Promote Equality of Opportunity’ (2002) 21(1) *Equal Opportunities International* 19.

¹⁵ For discussion, see Paul Chaney, ‘Post-Devolution Equality Agenda’ (n12).

¹⁶ Objective 5 of this Strategic Equality Plan (SEP) stated: ‘tackle barriers and support disabled people so that they can live independently and exercise choice and control in their daily lives’. See, Welsh Government, ‘Framework for Action on Independent Living’ (2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018, 9, citing Welsh Government, ‘Strategic Equality Plan and Objectives 2012-2016’ (2012) <<https://gweddiill.gov.wales/docs/dsjlg/publications/equality/120405sepfinal-en.pdf>> accessed 30 July 2019. In the subsequent SEP, this objective is the first stated priority and is revised to make explicit reference to a right to independent living. See Chapter 10, Section 2.

¹⁷ The Welsh Government Equality Forum is explained in Chapter 3, Section 3.

¹⁸ Jeremy Miles AM, Counsel General for Wales, ‘A Human Rights Act for Wales?’ (Eileen Illtyd Memorial Lecture on Human Rights, 15 November 2018) (*Swansea University*, undated) <<https://www.swansea.ac.uk/media/The%20Eileen%20Illtyd%20Memorial%20Lecture%20on%20Human%20Rights.%20Counsel%20General%20Nov%202018%20FINAL%20v28.11.18.pdf>> accessed 15 March 2019; See also Julie James AM, Leader of the House and Chief Whip, in National Assembly for Wales, Plenary Debate, 12 December 2018, para 170 <<http://record.assembly.wales/Plenary/5372#A47392>> accessed 13 March 2019.

The Assembly partially incorporated the UN Convention on the Rights of the Child into Welsh legislation in 2011,¹⁹ and is particularly mindful of its duties under this Convention. To date, however, the incorporation of the UNCRC into Welsh domestic legislation has been resisted²⁰ although recent discussion in the Assembly indicates that this is being reconsidered. At the time of writing, a cross party group on human rights had recently been established at the Assembly, and the possibility of the introduction of a Bill that would incorporate various UN Conventions into Welsh legislation – including the UNCRC – was being discussed.²¹

‘Community’ and communitarianism has no such legal underpinnings in Wales but is fundamental to the Welsh Government approach to the public sector, underpinning the ideas of mutuality, inclusion and collectivism. In Welsh Government policy, the concept of ‘community’ is multi-faceted. It expresses the existence of a broad sense of ownership, belonging and mutual interests,²² and the importance of local ‘sustainable’ communities to Welsh public life and to their populations.²³ In terms of social care, the Welsh Government inherited from Westminster a focus on support provision in community settings.²⁴ However, the values of ‘community’ or ‘communities’ have historically been emphasised as a general principle in Welsh Government discussion of the public sector and go well beyond the idea of community provision. Public services, including social services and social care, are viewed as a means of developing and strengthening local communities as well as supporting individuals;²⁵ and local communities are constructed as a core form of

¹⁹ Section 1(1) of the Rights of Children and Young Persons (Wales) Measure 2011 requires the Welsh Government to have due regard to the requirements of the UNCRC when exercising any of its functions.

²⁰ See Chapter 11.

²¹ National Assembly for Wales, Record of Proceedings, Plenary Debate, 12 December 2018, paras 169 – 261 and particularly para 229 <<http://record.assembly.wales/Plenary/5372#A47392>> accessed 13 March 2019.

²² Welsh Assembly Government, ‘Making the Connections: Delivering Better Services for Wales’ (2004)

<<http://www.wales.nhs.uk/technologymis/english/resources/pdf/Making%20the%20connections.pdf>> accessed 22 July 2019, Introduction.

²³ Welsh Assembly Government, ‘Making the Connections - Delivering Beyond Boundaries: Transforming Public Services in Wales’ (2006)

<https://webarchive.nationalarchives.gov.uk/20080109181520/http://new.wales.gov.uk/dps/publications/policies/delivering/Responsee?lang=en> accessed 22 July 2019, Introduction.

²⁴ See Chapter 3, section 6.1.

²⁵ Welsh Assembly Government, ‘Fulfilled Lives, Supportive Communities: A Strategy for Social Services in Wales over the Next Decade’ (2007)

support for all people including those in need of particular assistance.²⁶ Participation in community life is seen as important for both the citizen and the community, strengthening both.²⁷

The final area of potential adjacency between independent living and the Welsh Government communitarian narrative is that of 'wellbeing'.²⁸ The importance of wellbeing in Welsh Government policy is indicated by its prominence in two recent pieces of Welsh legislation – the Social Services and Well-being (Wales) Act 2014 (discussed in Chapter 11) and the Wellbeing of Future Generations (Wales) Act 2015. Wellbeing was not connected to independent living by the disabled people's movement.²⁹ Indeed, it is an idea that tends to be used in government and public sector circles rather than by the public.³⁰ In Welsh policy, wellbeing is connected with multiple areas. A 2002 document 'Well Being in Wales' connected wellbeing to health and also to equality, social inclusion and sustainable development³¹ – the three 'cross-cutting guiding themes' noted earlier in this section to have been identified by Chaney. Wellbeing is not defined in this document, but is associated

<<http://gov.wales/dhss/publications/socialcare/strategies/fulfilledlives/fulfilledlivese.pdf?lang=en>> accessed 23 February 2018, Chapter 1.

²⁶ Ibid.

²⁷ Ibid.

²⁸ 'Wellbeing' is spelt in a number of ways when used by the Welsh Government. This thesis uses the spelling 'wellbeing' in all cases other than in references to named documents.

²⁹ Wellbeing was connected to independent living on only one occasion in the Anglo-British DPM dataset texts. In the extracts that used the term 'independent living' in the Welsh DPM texts, three connected independent living to wellbeing, all of which were related to discussion of whether independent living should form part of the wellbeing duty in the (then forthcoming) Social Services and Well-being (Wales) Act 2014. In the Welsh texts more widely, there were six further references to wellbeing.

³⁰ In 2008 a report on the use of the term 'wellbeing' for the Department for Children, Schools and Families noted that 'its wide use in public discourse may not extend to all of DCSF's stakeholder groups - is not yet present in the unprompted discourse of parents and children and indeed is not well understood by these groups'. Gill Ereaut and Rebecca Whiting, 'What Do We Mean by 'Wellbeing'? And Why Might It Matter?' (DCSF 2008). Wellbeing has also recently emerged as a concept that may be used as an indicator of social progress. In this capacity it has been promoted as a measure that challenges or complements the use of gross domestic product as an indicator of national prosperity and performance and a tool to develop public policy. Gus O'Donnell and others, 'Wellbeing and Policy' (Legatum Institute 2014) <<https://li.com/docs/default-source/commission-on-wellbeing-and-policy/commission-on-wellbeing-and-policy-report---march-2014-pdf.pdf>> accessed 20 February 2019; Alejandro Adler and Martin EP Seligman, 'Using Wellbeing for Public Policy: Theory, Measurement and Recommendations' (2016) 6(1) *International Journal of Wellbeing*, 1. In this capacity, wellbeing is now used by the Office of National Statistics (ONS). ONS, 'Well-being' (undated) <<https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing>> accessed 20 February 2019.

³¹ Welsh Assembly Government, 'Well Being in Wales: Consultation Document' (Welsh Assembly Government 2002) <<http://www.wales.nhs.uk/documents/file1-full-doc-e.pdf>> accessed 31 October 2018.

with various matters including: engagement in the community, happiness, confidence, self-esteem, safety, financial and other security, ready access to services and facilities, access to care and support if needed, and ‘overall quality of life’. Clear areas of adjacency therefore exist between the Welsh Government’s notion of wellbeing and the narrative of independent living – both in specific matters, such as community engagement, and in a general desired outcome of the ability to lead fulfilled lives. A ‘well-being duty’ underpins the Social Services and Well-being (Wales) Act 2014, where it is explicitly connected to independent living. This is discussed in Chapter 11.

Wellbeing is profoundly imprecise in its meaning, with a content and construction that are subject to fluidity and change.³² An analysis by the New Economics Foundation found that a positive attribute of wellbeing in the policy context included the fact that it is:

... a good fit with several emerging agendas that are not currently using the language of well-being.³³

Wellbeing is therefore valuable in the policy environment precisely *because of*, rather than *despite*, its highly amorphous and ambiguous quality.

³² See, for example, Ereaut and Whiting (n30); Adler and Seligman (n30); Rachel Dodge and others, ‘The Challenge of Defining Wellbeing’ (2012) 2(3) *International Journal of Wellbeing* 222. The Health and Social Care Committee of the Welsh Government has noted that there is no clear definition of ‘wellbeing’ across any of the legislative contexts in which it was found. National Assembly for Wales Health and Social Care Committee, ‘Social Services and Well-being (Wales) Bill: Stage 1 Committee Report’ (National Assembly for Wales July 2013) <[http://www.assembly.wales/Laid%20Documents/CR-LD9418%20-%20Health%20and%20Social%20Care%20Committee%20%20Stage%201%20Committee%20Report,%20Social%20Services%20and%20Well-being%20%20\(Wales\)-18072013-248230/cr-ld9418-e-English.pdf](http://www.assembly.wales/Laid%20Documents/CR-LD9418%20-%20Health%20and%20Social%20Care%20Committee%20%20Stage%201%20Committee%20Report,%20Social%20Services%20and%20Well-being%20%20(Wales)-18072013-248230/cr-ld9418-e-English.pdf)> accessed 15 May 2019, 189. In the Welsh context the meaning of wellbeing is distinct under each of the two statutes in which it forms a central principle. See this comment by the Welsh Government: ‘The use of the term “well-being” in the [2015] Act and the Social Services and Well-being (Wales) Act 2014 (“the SS&WB Act”) are complementary. The meaning of “well-being” in the SS&WB Act applies only for the purpose of that Act. “Well-being” in the SS&WB Act is defined in relation to a “person”, whereas “well-being” in the [2015] Act is in relation to our economy, society, environment and culture across Wales.’ Welsh Government, ‘Shared Purpose: Shared Future: Statutory Guidance on the Well-being of Future Generations (Wales) Act 2015’ (2016) <<https://gov.wales/docs/desh/publications/160915-spsf-1-core-guidance-en.PDF>> accessed 31 October 2018, paras 21-22.

³³ New Economics Foundation, ‘Measuring Well-Being in Policy: Issues and Applications’ (NEF, 2008) <https://b.3cdn.net/nefoundation/575659b4f333001669_ohm6iioqp.pdf> accessed 19 February 2019.

There were therefore five areas of particular or potential adjacency between independent living and the Welsh Government communitarian narrative: inclusion and participation, equality, human rights, community, and wellbeing. Of these, the Welsh Government has formally connected independent living to specific legal obligations in relation to equality and wellbeing. A common aspect of these adjacent concepts is their flexibility. The elasticity of meaning of well-being, community and 'inclusiveness' in the Welsh context is described above. Equality and rights are broadly adopted by governments of all political leanings and are adaptable to various contexts – equality, and particularly equality of opportunity, has been referenced as an aim of Westminster governments for decades,³⁴ and rights are a mantra for democratic governments of most persuasions.³⁵ All of these adjacent ideas were therefore likely to be areas of struggle over meaning and were susceptible to being deployed in policy to suggest consensus and obscure conflict. This flexibility of content is, indeed, likely to be a contributing factor in their existence as 'adjacent' concepts.

3. Independence and a struggle for meaning

One overarching concept within independent living which gave rise to a particular site of struggle for meaning was that of independence. Independence is, clearly, central to the independent living counter-narrative. In addition to the use of the phrase 'independent living', it is argued in Chapter 2 that the introduction of the idea of independence was one of the distinctions between independent living and the social model.³⁶

³⁴ Ewart Keep and Ken Mayhew, 'Inequality – "Wicked Problems"', Labour Market Outcomes and the Search for Silver Bullets' (2014) 40(6) Oxford Review of Education 764. In relation to the New Labour years, see, Peter Taylor Gooby, 'Blair's Scars' (2000) 20(3) Critical Social Policy 331. In relation to the Cameron years see, Conservative Party, 'Raising the Bar, Closing the Gap' (Policy Green Paper No. 1, 2007) <<http://www.educationengland.org.uk/documents/pdfs/2007-conservative-policy.pdf>> accessed 22 July 2019.

³⁵ As a basic example, 47 states are signatories to the European Convention on Human Rights. Nearly every sovereign state is a signatory to the Universal Declaration of Human Rights - see EHCR, 'What is the Universal Declaration of Human Rights?' (last updated 19 November 2018) <<https://www.equalityhumanrights.com/en/what-are-human-rights/what-universal-declaration-human-rights>> accessed 22 July 2019.

³⁶ Section 5.

A notable aspect of many of the fragments of independent living was their existence and importance in documents from the earliest days of the disabled people's movement, prior to the rise of independent living itself.³⁷ The founding document of UPIAS, for example, emphasised inclusion, participation, contribution to society, rights, equality, and opportunity. In addition, the definitional elements of independent living – choice and control – were forcefully articulated by the movement from the outset. The first paragraph of the founding document of UPIAS contains the statement:

The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society ...and to live where and how we choose with full control over our lives.³⁸

This statement could act as a succinct summary of many of the core principles of independent living. In the UPIAS documents, these themes were connected with *segregation* rather than independence. The acronym 'UPIAS' itself stood for the Union of the Physically Impaired Against Segregation.³⁹ There was no discussion in the dataset documents as to how or why certain themes were transferred from the

³⁷ In 1992, Maggie Davis said, 'Many of the ideas which currently cluster together under the banner of 'independent living' have been part and parcel of the struggles and aspirations of individual disabled people, probably as long as disabled people have dreamed. of freedom and independence.' Maggie Davis, 'Personal Assistance - Notes on the Historic' (presentation at BCODP seminar "Making Our Own Choices", 1992)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019, 15. There is discussion of this point on various occasions in Chapter 6.

³⁸ UPIAS, 'Policy Statement' (1974 amended 1976)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-UPIAS.pdf>> accessed 16 November 2016. This statement was repeated in UPIAS, 'The Union of the Physically Impaired Against Segregation and The Disability Alliance discuss Fundamental Principles of Disability' (1976) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-fundamental-principles.pdf>> accessed 16 November 2016.

³⁹ In this respect UPIAS echoed the language being used by the civil rights movement in the US, although it is not clear that this was intentional. See Chapter 2, section 4, including footnote 100. It is worth noting, however, that the segregation of African Americans mirrored the principles of apartheid that existed contemporaneously in South Africa, and that Finkelstein – one of the founder members of UPIAS – was an anti-apartheid campaigner who had come to Britain from South Africa as a political exile following his imprisonment there. Mike Oliver, 'Vic Finkelstein Obituary' *The Guardian* (London, 22 December 2011) <<https://www.theguardian.com/society/2011/dec/22/vic-finkelstein>> accessed 10 June 2018.

principle of integration to that of independent living, although it was clear that the term 'independent living' was borrowed from the US.⁴⁰ Regardless of its origin, the use of this language introduced a series of ideas and narrative relationships that would add richness, but also complexity – both to the counter-narrative itself, and to its transition into the policy context.

The use of the idea of independence by the UK movement was not straightforward. The complex relationship of disabled people to 'dependence' – which was expressed as both an oppressive master narrative and a natural state for disabled and non-disabled people alike – is discussed in Chapter 6.⁴¹ The language of independence countered this master narrative by default. Independence was, however, connected to a potentially damaging master narrative of its own. In 1984, in one of the dissenting texts, Ken Davis wrote:

Use of the term “independent living” causes problems of understanding. People not directly concerned with disability issues usually interpret the term in an ordinary, commonsense way, i.e. that disabled people want to be self-reliant without help; or that we did not wish to be dependent or to rely on other people; or that we wanted to think and do things for ourselves.⁴²

Davis's expression of 'an *ordinary, common sense*' interpretation of independence reflected a master narrative of independence as self-reliance, although it also encompassed the idea of self-determination, suggesting that these ideas are connected. Similarly, Oliver identified three different meanings of independence – independent living, self-reliance and a lack of a need to use state-funded support.⁴³ Oliver noted that disabled people frequently intended the first, while others intended

⁴⁰ Ken Davis, 'Notes on the Development of the Derbyshire Centre for Integrated Living (DCIL)' (Derbyshire Coalition of Disabled People, December 1984), <<http://disability-studies.leeds.ac.uk/files/library/DavisK-earlydcil.pdf>> accessed 1 June 2015, para 4.2.

⁴¹ Section 2.

⁴² Davis, 'Notes' (n40), para 4.1.

⁴³ Mike Oliver, 'Where Will Older People Be? Independent Living versus Residential Care' (Conference: The Care and Management of Older People with Complex Needs, London, June 2001) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Oliver-where-will-older-people-be.pdf>> accessed 21 September 2017.

the latter two.⁴⁴ If disabled activists were to reclaim and reconstruct the disabled identity through a counter-narrative of *independent* living, they therefore had to deal with the difficulty that independence contained dominant ideas of self-reliance, self-help, looking after oneself and a lack of need for welfare state support. By deploying the language of independence as an identifying concept, disabled activists were *starting* with an idea that imposed a struggle for meaning.

The requirement for a reconceptualisation of independence was acknowledged by activists. It is stated in Chapter 2, section 5 that one typical element of definitions of independent living was the need for ‘a challenge to the usual interpretation of “independent”’.⁴⁵ As early as 1986 Brisenden stated:

... it is important to note the sense in which we use the word ‘independence’ because it is crucial to everything we are saying. We do not use the term ‘independent’ to mean someone who can do everything for themselves, but to indicate someone who has taken control of their life and is choosing how that life is led...⁴⁶

This distinction is also made in both the definition of independent living devised by the DRC and the explanation of independent living devised by Disability Wales:

⁴⁴ Ibid. In relation to state policy, feminist scholars have noted for decades the connection of ‘independence’ to a discourse of self-reliance, and particularly a lack of a need for contact with state structures. See, for example, Nancy Fraser and Linda Gordon, “Dependency” Demystified: Inscriptions of Power in a Keyword of the Welfare State’ (1994) *Social Politics* 4; Martha Fineman, *The Autonomy Myth: A Theory of Dependency* (New Press 2004).

⁴⁵ Jenny Morris, ‘Independent Living and Community Care: A Disempowering Framework’ (2004) *Disability & Society* 9(5) 427, 427.

⁴⁶ Simon Brisenden, ‘Independent Living and the Medical Model of Disability’ (1986) *Disability, Handicap & Society* 1(2) 173, 178. This challenge went back to the early US independent living movement. Barnes and Mercer note that the students in Berkeley sought to make themselves ‘independently dependent’. Colin Barnes and Geof Mercer, *Independent Futures: Creating User-Led Disability Services in a Disabling Society* (Policy Press 2006), 31. Barnes and Mercer do not state whether this was the language used by the Berkeley students themselves, or whether this is their own interpretation. Similarly, Shapiro states that Ed Roberts, one of the group of Berkeley students ‘redefined independence as the control a disabled person had over his life. Independence was measured not by the tasks one could perform without assistance but by the quality of one’s life with help’. J Shapiro, ‘From Charity to Independent Living’ in J Shapiro (ed), *No Pity: People with Disabilities Forging a New Civil Rights Movement* (Random House, 1993), 51, cited in Susan Peters, Susan Gabel and Simoni Symeonidou, ‘Resistance, Transformation and the Politics of Hope: Imagining a Way Forward for the Disabled People’s Movement’ (2009) *Disability & Society* 24(5) 543.

This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.⁴⁷

Independent Living does not mean that disabled people should have to live in isolation, do everything for themselves or be completely independent of services.⁴⁸

This distinction was also discussed in the negotiations on the drafting of Article 19 of the UNCRPD. During these negotiations, various delegates argued that the idea of 'independence' related to the ability of people to live on their own or do things without a need for support.⁴⁹

In its 'natural' meaning, independence encompasses the ideas of self-reliance and self-determination as well as other matters. Among six meanings given for the adjective 'independent' in the Oxford English Dictionary are:

- 1.a. Not depending upon the authority of another, not in a position of subordination or subjection; not subject to external control or rule; self-governing, autonomous, free;...
3. Not depending on something else for its existence, validity, efficiency, operation, or some other attribute; not contingent on or conditioned by anything else;
4. Not dependent or having to rely on another for support or supplies.⁵⁰

⁴⁷ Disability Rights Commission, 'Policy Statement on Social Care and Independent Living' (unpublished, October 2002), sent to the author by e-mail from the Equality and Human Rights Commission (28 May 2015).

⁴⁸ Disability Wales / Anabledd Cymru, 'Manifesto for Independent Living' (2011) <http://www.disabilitywales.org/wordpress/wp-content/uploads/Manifesto_for_IL_E.pdf> accessed 11 November 2016, 6.

⁴⁹ Arlene Kanter, *The Development of Disability Rights under International Law* (Routledge 2015), Chapter 2. Israel noted that the use of the term 'independence' might be interpreted in a way that actively went against the spirit of the Convention. János Fiala- Butora, Arie Rimmerman, and Ayelet Gur, 'Article 19: Living Independently and Being Included in the Community' in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (OUP 2018), 534.

⁵⁰ Oxford English Dictionary (online edition) <<http://www.oed.com/view/Entry/94325?rskey=gvjSnL&result=1&isAdvanced=false#eid>> accessed 19 June 2019. Similarly, 'independence' is defined as: "1.a. The condition or quality of being

In the independent living counter-narrative, however, the idea of independence needed to be conceptualised in a very specific way, with the element of self-reliance rejected and meanings related to self-determination brought to the fore. A number of the Anglo-British DPM dataset texts, particularly those authored by Morris, contained discussion on this theme and it was also seen in the Welsh DPM dataset.⁵¹

Beresford described this as ‘turn[ing] traditional notions of independence on their head’.⁵² Essentially, the movement was attempting to develop a counter-narrative to master narratives of independence and perform what Godrej described as an act of ‘linguistic reclamation’.⁵³

Given the centrality of this ‘redefinition’ of independence to independent living, one section of the coding exercise examined how far the language of independence was used in a ‘reclaimed’ or a ‘typical’ sense. References to independence (as opposed to independent living) were coded according to the use of independence as ‘synonymous with independent living’⁵⁴ or as ‘self-reliance’ – in the form of being able to do things for oneself or lacking a need for support.⁵⁵ A further code was

independent; the fact of not depending on another (with various shades of meaning: see the adj.); exemption from external control or support; freedom from subjection, or from the influence of others; individual liberty of thought or action. Rarely in bad sense: Want of subjection to rightful authority, insubordination.” The Keyword Project, which examines words that are ‘contested in social debate in English’ has an entry relating to independence that considers its genealogy and multiple meanings. See, Keywords Project, ‘Independent’ (*University of Pittsburgh and Jesus College, University of Cambridge*, undated) <http://keywords.pitt.edu/keywords_defined/independent.html> accessed 10 June 2018.

⁵¹ Disability Wales / Anabledd Cymru, ‘Manifesto for Independent Living’ (n48) 6; Letter from Vin West on behalf of Arfon Access Group / Grwp Mynediad Arfon to Sarah Beasley, Clerk to Health & Social Care Committee, (15 March 2013) (accepted as a response to the consultation on the Social Services and Well-being Wales Bill) <www.senedd.assembly.wales/documents/s15313/SSW%2043%20Arfon%20Access%20Group.pdf> accessed 2 January 2017.

⁵² Peter Beresford, *What Future for Care?* (Joseph Rowntree Foundation 2008), 10.

⁵³ Farah Godrej, ‘Spaces for Counter-Narratives: The Phenomenology of Reclamation’ (2011) 32(3) *Frontiers: A Journal of Women Studies* 111. See Chapter 4, section 7.4. Morris (in a non-dataset text) argued that the idea of ‘care’ also needed to be ‘reclaimed’. ‘We need to reclaim the words ‘care’ and ‘caring’ to mean ‘love’ to mean ‘caring *about*’ someone rather than ‘caring *for*’, with its custodial overtones.’ Jenny Morris, *Independent Lives: Community Care and Disabled People* (Macmillan 1993) 174, original emphasis, cited in Beresford, *What Future* (n52) 9.

⁵⁴ References to independence in the form of self-determination were also sought, but in the Anglo-British DPM texts, this form of independence was entirely found within references that were synonymous with independent living. In the Welsh dataset there were both references that were synonymous with independent living and references to self-determination.

⁵⁵ Certain references were excluded from this exercise. See Chapter 5, section 5.2.2.

created for extracts in which it was not possible conclusively to state whether a reference to independence related to either of these concepts.⁵⁶ This section examines how independence was conceptualised in both the Anglo-British and the Welsh DPM dataset texts.

In both these datasets, the language of independence was deployed to refer to both the ideas of independent living and to self-reliance, although the latter was less common.⁵⁷ In the Anglo-British DPM dataset references to independence in the form of independent living increased over time. While documents prior to the rise of independent living (unsurprisingly) contained no such references, from 1996 onwards 'independence' was far more commonly used synonymously with independent living than to refer to self-reliance. In many of these cases the term 'living independently' was used by some authors simply as a stylistic device, to avoid repetition of the phrase 'independent living' or for grammatical ease.

The Framework for Action on Independent Living is due to be published in summer 2012. It will set out the action to be taken to promote the rights of disabled people to live independently and exercise the same choices as other citizens.⁵⁸

As noted in Chapter 3, the phrase 'living independently' is used in the UNCRPD, and certain uses of this phrase in later texts were conscious echoes of Article 19.

Certain of the references to independence in the form of independent living emphasised the ideas that disabled people were able to achieve independence in the form of self-determination, regardless of impairment and a need for support.

⁵⁶ This was not to say that these latter references had no meaning, but simply that they could not definitively be stated to refer predominantly to one of these ideas.

⁵⁷ In the Anglo-British DPM dataset, of the 116 coded references to independence, 50 were synonymous with independent living, while 36 related to self-reliance. Thirty coded references could not be conclusively attributed to one or the other. In the Welsh DPM documents, of 19 coded references to independence, seven referred to independent living or to self-determination and three to self-reliance, while nine could not be definitively attached to either idea.

⁵⁸ Disability Wales, 'Additional Written Evidence submitted by Disability Wales (IL 39A) (undated), 170. Published in, Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (2011) (pages 170-171) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019.

Indeed, support was seen as necessary to enable the reconceptualised form of independence:

If a P.A has to push a wheelchair, help a disabled person dress or reach for a book, it should be seen as enhancing the disabled persons ability to live independently.⁵⁹

Others stressed the importance or entitlement of independence to disabled people.

There should be a basic enforceable right to independent living for all disabled people. Policy objectives for social care services need to include guaranteed minimum outcomes, backed up by a right to independence.⁶⁰

In contrast, references to independence in the form of self-reliance decreased over time in the DPM dataset. The earliest documents⁶¹ used independence in line with the master narrative, referring to the ability to do things for oneself, and particularly to earning capacity. These references decreased and disappeared in the later documents, with the last occurring in 2004.⁶² Where such references did appear, they were on occasion constructed as the product of the infiltrated self, or a form of oppression of disabled people, or both:⁶³

The person most likely to be vulnerable to the effects of such denials of her disability is the person who is too isolated from other people with disabilities to be able to draw upon our shared strength, and who is trying to achieve a false independence by being as able bodied as possible and not making any demands on other people. That kind of 'independence' is no independence at

⁵⁹ Stewart Bracking, 'Independent/Integrated Living - A Brief Overview' (paper presented at BCODP conference: 'Making Our Own Choices', 1992) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 18 November 2016, 13.

⁶⁰ Gerry Zarb, 'Independent Living and the Road to Inclusion' in C Barnes and G Mercer (eds) *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004), 191-192.

⁶¹ These predated the rise of independent living in the UK and the use in the UK of the phrase 'independent living'.

⁶² In Zarb, 'The Road to Inclusion' (n60). Prior to that the most recent had been 1998. A large number of these references occurred in two texts: Colin Barnes, *'Cabbage Syndrome': The Social Construction of Dependence* (Falmer Press 1990) (Chapter 6: 'Participation and Control') and AT Sutherland, *Disabled We Stand* (Souvenir Press 1981) (Chapter 7: The Role of 'Disabled Person').

⁶³ These references occurred particularly in Sutherland (n62).

all, because it consists of living one's life on terms that are dictated by the able bodied and despising one's body rather than taking pride in oneself as a person with a disability.⁶⁴

In the Anglo-British dataset, the references to independence that were essentially ambiguous in their connection with either self-reliance or self-determination existed from the earliest document to the most recent. Certain of these extracts connected independence with ideas of self-determination (including choice and control), but did not exclude other potential meanings, including self-reliance:

DDPOs said they were concerned that there is now a reduction in choice, control and independence.⁶⁵

In the case of the Welsh documents, certain of these occurred in prominent situations, including in the Disability Wales mission statement, which read:

[Disability Wales] is the national association of disabled people's organisations, striving to achieve equality, rights and independence for all disabled people...⁶⁶

The texts therefore demonstrated that while there was a strong attempt to 'reclaim' the concept of independence in both the Anglo-British and Welsh DPM datasets, this was only partially accomplished. The uses of independence to refer to self-reliance, even when this referred to *external* ideas, and the ambiguous uses blurred the

⁶⁴ Sutherland (n62) 92

⁶⁵ Inclusion London, 'Evidence of Breaches of Disabled People's Rights under the UN Convention on the Rights of Persons with Disabilities' (2015) <<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/equality-and-human-rights/evidence-of-breaches-of-disabled-peoples-rights-under-the-un-convention-on-the-rights-of-persons-with-disabilities/>> accessed 2 January 2017. 46.

⁶⁶ Disability Wales / Anabledd Cymru, 'Manifesto for Independent Living' (n48), 6. In addition, while the Disability Wales 'Disabled People's Manifesto' (2016) contained only one reference to independent living (in a call for proposed legislation in the form of an Independent Living Bill), it held four ambiguous references to independence. Disability Wales / Anabledd Cymru, 'Disabled People's Manifesto' (2016) <<http://www.disabilitywales.org/wordpress/wp-content/uploads/DW-Manifesto-BILINGUAL-FINAL.pdf>> accessed 9 November 2016 (pages unnumbered). One of these was a call for 'a Commission of Inquiry involving disabled people and their organisations to consider options to strengthen the enforcement of disabled people's rights, equality and independence in Wales'.

distinction between the elements of independence that needed to be separated in the independent living counter-narrative. This confusion was stronger in the Welsh texts, and the later Anglo-British texts, in which independent living was less frequently directly referenced but ambiguous uses of ‘independence’ continued to occur.⁶⁷

3.1. Independence as a site of dissent

The existence of ‘dissenting’ texts is discussed in Chapter 5. These texts were written by individuals who were in some way connected to the movement but who were expressing ideas about independent living that were distinct from, or questioned, those that were typically found in the Anglo-British DPM dataset. The distinguishing feature of these texts was that they were in some way *critical* of central ideas held within independent living.⁶⁸ The use of the language and concept of independence was a core area of disagreement between the dissenting and non-dissenting texts. Two issues were raised in the dissenting texts about the focus on independence – the potential for confusion arising from the attempt to separate out the ideas of self-reliance and self-determination, and the connection of independence to individualism. This latter concern revealed a struggle over the essential character of independent living, and specifically how far independent living should promote the values of the self.

Davis and Finkelstein – authors with a shared history as UPIAS members – both discussed the difficulty in separating self-determination and self-reliance and the potential confusion that might arise from this. Finkelstein was scathing on this theme, arguing strongly that disabled people were associating themselves with potentially damaging narratives of dependency. In 2007, commenting on a DPO leaflet which

⁶⁷ For discussion of the decrease in the number of references to independent living in the later texts see Chapter 6, Section 3.

⁶⁸ For an explanation of the dissenting texts and information about them and their authorship, see Chapter 5, section 4.1.5.

stated 'it is still very hard to live independently because we do not have enough support to have freedom and choice',⁶⁹ he responded:

So, after all, disabled people cannot be 'independent' without state 'support' – disabled people's 'independence' is 'dependent'!! I don't think you need to be a psychologist to recognise the dominant message this demonstration will feed the 'non-disabled' public.⁷⁰

Finkelstein had earlier (in a non-dissenting text dated 1998) suggested that the use of the language of independence did not demonstrate a challenge to the existing discourse, so much as subjection to it, implicitly suggesting notions of the infiltrated self:

.... the heading 'independent living'... can be rather confusing because the term 'independence' is well established in the language of 'care' and perhaps reflects the extent to which the culture of care has been absorbed into the consciousness of prevailing service users.⁷¹

All three of the dissenting authors (Davis, Finkelstein and Shakespeare) expressed concerns about the commitment to independence because of the principles of individualism associated with it. In his 1984 piece, Davis expressed profound scepticism about the individualistic attitudes which he considered underpinned many of the themes connected to independent living. In particular, Davis discussed the principles of choice and control (described as 'self-control') in uncompromising terms.

⁶⁹ Vic Finkelstein, 'The "Social Model of Disability" and the Disability Movement' (2007) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-The-Social-Model-of-Disability-and-the-Disability-Movement.pdf>> accessed 2 January 2017, 12. Finkelstein cites this as an undated flyer by 'Our Lives R4 Living', circulated in 2006. The leaflet itself could not be traced.

⁷⁰ Ibid 12. The reference to psychology relates to the Finkelstein's professional career as a psychologist.

⁷¹ Vic Finkelstein, 'Re-Thinking "Care" in a Society Providing Equal Opportunities for All' (discussion paper commissioned by the World Health Organisation, March 1998) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-finkelstein2.pdf>> accessed 18 November 2016.

To seek the ability to decide and choose what one personally wants, to seek to assume and establish self-control and self-determination are potent mental constructs which can have devastating effects in the real world. For example, it can lead disabled people into using human and other resources simply as the means to achieve personal ends, to be discarded or changed as the process of identifying personal choices and creating personal solutions also changes.⁷²

Even at this early stage, choice and control were therefore perceived to be connected to *individual* self-determination. Davis also connected this individualism to the language of independence. While he acknowledged the importance of independence for disabled people who had been subjected to enforced group living and a lack of control over the most basic aspects of one's own life,⁷³ he also argued that independence, in focusing on the individual, was premised on a 'commitment to self'.⁷⁴ He connected this with models of independent living emerging from the USA that were explicitly and intentionally based on consumer approaches and market ideals. Davis was supported in this by Finkelstein, whose concern about the individualism of rights is explored in Chapter 6, section 4.3.⁷⁵ Finkelstein shared Davis's concern about consumer models of support, particularly direct payments,⁷⁶ arguing that these models were too closely connected with political ideologies that brought the principles of the market into the care system and that this proximity compromised the disabled people's movement.⁷⁷ Other authors, including Oliver, have also expressed these concerns.⁷⁸ Davis, Finkelstein and Oliver therefore

⁷² Ken Davis, 'Notes' (n40) para 4.4.

⁷³ 'It may be argued that [the term 'independent living'] is a vital corrective for disabled people whose personal development has become subject to the control of others. It may be argued that it is a potent motivator to hold up the idea of independence before those who are denied it.' Ibid, para 4.3.

⁷⁴ Ibid para 4.3.

⁷⁵ In a text not included in the dataset, Shakespeare also contrasted the approaches taken by the UK movement, which largely focused on engagement in democratic processes, with those of the US movement, which was more individualised and consumer-oriented. Tom Shakespeare, 'Disabled People's Self-Organisation: A New Social Movement?' (1993) 8(3) *Disability, Handicap & Society* 249.

⁷⁶ Finkelstein 'Social Model' (n69) 11.

⁷⁷ Ibid, 11-12, '...the disability movement is no longer setting the agenda for our emancipation – instead, we've become prisoners of a market that sets the agenda for our movement!'

⁷⁸ Oliver alludes to the 'warnings' on this theme given by Finkelstein. Michael Oliver, 'Welfare and the Wisdom of the Past' (*Disability Now*, February 2013) <<http://www.disabilitynow.org.uk/article/welfare-and-wisdom-past>> accessed 19 August 2013.

forewarned of difficulties that – as noted in previous chapters – are now widely discussed.

Both Davis and Finkelstein, echoing their common UPIAS connection,⁷⁹ rejected the terminology of ‘independent living’ in favour of ‘integrated living’. Davis contrasted the ‘commitment to self’ that he perceived in independent living with a ‘commitment to society’ through *integrated* living,⁸⁰ which he sought to achieve by ‘disabled and non-disabled people working together’ for the mutual benefit of both.⁸¹ These values underpinned the work of the Derbyshire Centre for Integrated Living (DCIL), which Davis was instrumental in founding in 1984, and its forerunner, the Derbyshire Coalition of Disabled People (DCDP).⁸² They had also been present in the Grove Road scheme, initiated by Ken and Maggie Davis, in which disabled and non-disabled tenants derived mutual benefit.⁸³ Both DCIL and DCDP aimed to ensure the involvement of disabled people in the management structures of agencies such as health authorities and social services.⁸⁴ Similar ideas had been considered by Davis and Finkelstein as members of UPIAS. One of the earliest documents in the Anglo-British DPM dataset, the 1975 UPIAS ‘Fundamental Principles’, written largely by Finkelstein, set out a vision of a system in which disabled people would sit on panels, as experts alongside others, to conduct assessments for particular forms of support and adjustment on an individual level and to consider more broadly the ways in which social hurdles that exclude disabled people could be overcome. This was seen as a means of placing disabled people at the centre of social development, with non-disabled people acting in their service, as a way of developing solidarity, confidence and skills on the part of disabled people, and as a means of building a

⁷⁹ UPIAS, it will be remembered, stood for the Union of the Physically Impaired Against Segregation.

⁸⁰ K Davis, ‘Notes’ (n40) para 4.3.

⁸¹ Davis, ‘Notes’ (n40) para 5.1. Certain early documents in the dataset, particularly those connected to BCODP, used the term ‘independent integrated living’ to cover both approaches. See, for example, BCODP, ‘Comment on the Report of the Audit Commission “Making a Reality of Community Care” (1987) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/BCODP-report-of-audit-comm.pdf>> accessed 19 November 2016.

⁸² Davis (n40); Ken Davis and Audrey Mullender, *Ten Turbulent Years: A Review of the Work of the Derbyshire Coalition of Disabled People* (University of Nottingham 1993).

⁸³ See Chapter 2, Section 4. The disabled tenants paid the non-disabled tenants for the support they provided.

⁸⁴ Davis (n40) para 5.1. The document indicates that this co-working extended to non-disabled people being represented on DCIL management structures. This is not excluded by other DPOs, although it is typically recommended that the minimum proportion of disabled people involved in the management of DPOs should be 75 per cent. See Chapter 2, Section 2.

more generally inclusive society. They hinted at ways in which ideas such as choice and control might be exercised in and through communitarian rather than individualistic arrangements.

These collective approaches to the liberation and social 'reconstruction' of disabled people contrasted with the more individualistic approach of direct payments that was more typically found in the Anglo-British DPM dataset and which was central to other DPOs. Hampshire Centre for Independent Living (HCIL), for example, also founded in 1984, constructed disabled people as 'consumers',⁸⁵ and focused on developing the use of direct payments⁸⁶ and on training and supporting individuals to 'survive in the community'.⁸⁷ These two earliest centres for independent / integrated living therefore demonstrate two distinct approaches to the development of independent / integrated living from the outset, broadly characterised by an inclination either to individualism or to collectivism. HCIL focused on individual responses, and individual control of money and resources; and DCIL on control through involvement with and influence on state structures through democratic processes. These approaches were not mutually exclusive or 'hard and fast'. DCIL supported the campaign for direct payments,⁸⁸ and HCIL advocated for and facilitated involvement in consultation processes and explored collective responses to need.⁸⁹ There was also a strong solidarity between these organisations⁹⁰ and commonalities in principles and aims. Both groups absolutely rejected institutional living and other forms of segregation. Both sought flexible support directed by disabled people to meet their self-assessed needs and live the life of their choosing on an equal basis with non-disabled people. And in both cases, a fundamental shift was required in the concept of 'services' or 'care' and in the power relations between local authorities and individuals.

In one dissenting text, Shakespeare also argued that the focus of the disabled people's movement on independence was misplaced. Shakespeare accepted many

⁸⁵ HCIL, 'HCIL Papers 1990: Independent Living' (1990) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-hcil.pdf>> accessed 16 November 2016.

⁸⁶ Davis (37) 18.

⁸⁷ Evans, 'The Role of CILs' (n3) p62.

⁸⁸ Davis (n86) 18.

⁸⁹ HCIL, 'HCIL Papers' (n85) .

⁹⁰ Davis and Mullender (n82).

of the aspects of independent living, including the 'distinction between physical and social dependency' and the need for a 'transfer of power from professionals to individual disabled people'. However, he also held that:

'[t]here can be too much stress on independence and autonomy within disability rights discourse'.⁹¹

Shakespeare shared the unease of Davis and Finkelstein about the individualistic connotations of independence and certain principles connected with independent living.⁹² In addition to concerns about the fragmentation of support and 'privatised relationships'⁹³ he suggested that the personal assistant role had potential for exploitation and overtones of servitude.⁹⁴ Shakespeare referenced feminist critiques to argue that independence functions as a means of marginalising particular sectors of the population, including disabled people.⁹⁵ His response was to suggest that the disabled people's movement should target not the exclusion of disabled people from independence, but the notion of independence itself, and the overwhelming importance placed on independence in western societies.

...perhaps it would be more effective to challenge the overall liberal tradition of independence and individualism, rather than to claim access to the notion for a particular excluded population.⁹⁶

⁹¹ Tom Shakespeare, *Help: Imagining Welfare* (Venture Press 2000) (Chapter 4: 'Helpful'), 76. Shakespeare also suggested that the disabled people's movement was 'fetishising independence', *ibid* 81.

⁹² Shakespeare also highlighted the 'contradiction between the collectivism of the disability movement and the individualism of the proposed solution to care'. *Ibid* 76.

⁹³ *Ibid* 68.

⁹⁴ *Ibid* 68. 'The danger is that cheap personal assistance schemes rely on the exploitation of the people who are employed to facilitate independence. The reservation that some commentators express about direct payments for independent living is that it marks a return to the era of personal service. Victorian novels unquestioningly assume the provision of servants.... It could be argued that the individual, privatised relationships promoted by the independent living movement risk emulating this tradition.'

⁹⁵ *Ibid*. 'The notion of independence is inherited from a liberal tradition which has historically marginalised those who are not male, not adult, and not physically able', 76.

⁹⁶ *Ibid*, 77.

Shakespeare is arguing here that the disabled people's movement should remove its ideas from those of the dominant narrative.⁹⁷ Following the feminist critiques, Shakespeare advocated that the disabled people's movement should focus instead on the values of interdependence – a value that was indeed highlighted in the non-dissenting texts.⁹⁸ Arguing, like many in the disabled people's movement, that interdependence is an inevitable part of the human condition, he suggested that this 'feminist ethic approach to independence', complemented by strategies for barrier removal and personal assistance, offered 'a broader strategy for empowering disabled people'.⁹⁹

Davis, Finkelstein and Shakespeare did not express their views in terms of master and counter-narratives. However, in these dissenting texts, they were essentially articulating concerns that, in using the language and certain of the ideas connected with 'independence', the disabled people's movement and independent living were compliant with a master narrative that was both undesirable in itself *and* particularly damaging to disabled people. There can be no doubt that independence carries strong elements of individualism. It expresses both the desire and the ability of people to decide and to do things for oneself, free from external interference and reliance on others. Independence – in any of its meanings – has to do with the distinction between the self and others. This held a compelling value for people forced into undesired and identity-negating situations, but it also pulled against the collectivist approach of the early movement and the social model of disability. Despite these voices, ultimately it was the language and principles of 'independence' in the form of 'independent living' that gained traction, rather than those of integration. The disabled people's movement in both Wales and the UK more broadly has continued to focus on collective as well as more individualistic approaches to independent living, but within the movement the language of

⁹⁷ His suggestion has been echoed by Fiona Kumari Campbell, who argues that if the emancipation of disabled people is to be effectively achieved, it is necessary not to seek inclusion in existing structures and ideas, but to reformulate them. Similar arguments have been made by activists in other fields. See, for example, Peter Tatchell, 'Beyond Equality: Why Equal Rights are Not Enough' (*Peter Tatchell Foundation*, 9 January 2018) <<https://www.petertatchellfoundation.org/beyond-equality-why-equal-rights-are-not-enough/>> accessed 12 March 2019.

⁹⁸ The idea of interdependence was seen as important to independent living. See Chapter 6, section 2.

⁹⁹ Shakespeare, *Help* (n91) 78. Beresford, who also discusses feminist approaches to care, echoes this point. Beresford, *What Future* (n52).

independent living has essentially gained the status of received wisdom, or a master narrative of its own.

3.2. Independence and relationships of countering and compliance

The previous section has demonstrated that the disabled people's movement in Wales also chooses to use the language of independence and has stressed the distinction between self-determination and self-reliance, emphasising their connection with the broader disabled people's movement and their commitment to core principles of independent living. In Wales, the use of the language of independence created potential relationships of both adjacency *and* collision between independent living and the Welsh Government communitarian narrative. The antipathy towards individualistic approaches within the Welsh Government might suggest a distaste for independence, given the focus in independence on the self as an animating feature. In contrast, the focus on communitarian and collective approaches and responses was potentially adjacent to the rejection of self-reliance expressed within independent living.

In relation to independence, however, the more important relationships were potentially those of countering and compliance with master narratives. In their discussion of countering and compliance, counter-narrative theorists argue that if a counter-narrative is to be effective, it must be understandable and palatable to the ingroup.¹⁰⁰ Independence has the benefit, in Western culture, of being almost universally lauded. In using the language of independence, disabled activists both resisted historical narratives of dependence and connected themselves with commonly held social values that appealed to disabled people but which were understandable and appreciated much more broadly. In tackling the concept of dependency head on, disabled activists made immediate reference to their narrative of oppression and resistance *and* emphasised their commonalities with non-disabled people and their narrative of equal social membership. In connecting disabled people

¹⁰⁰ See Chapter 4, section 7.2.

with a widely shared value, the language of independence itself implicitly refuted master narratives of 'otherness'.

Within independence however, the disabled people's movement had to counter certain aspects while leaving others intact, creating significant potential to confuse. The requirement for this act of linguistic reclamation created a risk *both* that on the transportation of the counter-narrative from the disabled people's movement independent living and independence would become conflated *and* that independence would be understood to convey any or all of its component meanings, including those that the movement had attempted to reject. By far the greatest risk in this scenario, as the dissenting authors pointed out, was that the language of independence connected independent living to a master narrative of self-reliance that was particularly damaging to disabled people. This was exacerbated by the fact that, in this master narrative, ideas of self-reliance and self-determination are connected. An individual with private financial means, for example, has many more choices than those with fewer resources, and consequently less need to 'depend' on support from others in certain respects. The narratives of both independent living and the social model sought to break this link, demonstrating that barrier removal and adequate support enabled self-determination *without* functional capacity. This effectively removed self-reliance from the concept of self-determination, but did not remove self-determination from that of self-reliance. The separation of the ideas of self-determination and self-reliance was therefore complex and unintuitive to readers steeped in master narratives of independence and unfamiliar with the ideas and heritage of the disabled people's movement. This complexity rendered the act of linguistic reclamation – and potentially the counter-narrative – precarious.

The ambiguous uses of independence in the DPM texts demonstrated the difficulty in separating the ideas of self-reliance and self-determination. Where a word 'naturally' refers to different ideas, an attempt at reclamation by removing and rejecting certain elements alone is problematic. It requires regular explanation and repetition as well as attention and mental agility on the part of the reader if the 'reclaimed' version is to be understood. Simply put, where the language of independence was used

synonymously with independent living, the reader might not interpret it as such.¹⁰¹ In addition, the use of the language of independence required external actors not simply to *accept* a highly specific form of language use, but critically – if independent living was not to be misunderstood or undermined – to *replicate* it when translating it into other contexts. These processes of interpretation and translation would be out of the control of the movement, and would affect how the counter-narrative was interpreted and implemented in policy contexts.

Certain of the texts from the DPM datasets indicated that these difficulties were occurring. Zarb, for example, (in the English context) noted that the level of a person's 'independence' was a critical element of the eligibility criteria for receiving social care services and that the idea of self-determination was explicitly incorporated into the definition of independence,¹⁰² but that in practice the elements relating to functionality were prioritised over self-determination.¹⁰³ In 2011, Morris stated that the idea of independent living was being 'overshadowed' by the use in government policy of the language of independence in the form of self-reliance.

The disabled people's movement has struggled for years to move away from a definition of 'independent' as 'doing everything for yourself'. ... this has been overtaken by the current emphasis on individuals being 'independent' by ... getting out and earning their living and looking after their families, and moving

¹⁰¹ For example, the 2015 Inclusion London Manifesto stated, 'The state must provide appropriate funding and support to enable disabled people and all people to live lives of equality, independence and dignity'. Inclusion London, 'Disabled People's Manifesto: Reclaiming Our Futures' (2013) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UK-Disabled-People-s-Manifesto-Reclaiming-Our-Futures.pdf>> accessed 2 January 2017, 2. Similarly, the Disability Wales 'Manifesto for Independent Living' articulated the purpose of Disability Wales as 'striving to achieve equality, rights and independence for all disabled people', n48, 2. Such statements relied entirely on the reader's own understanding of 'independence' which – even in a sympathetic audience – would be likely to be created and framed by, and entrenched in, master narratives of independence as self-reliance.

¹⁰² This document is, Department of Health, 'Fair Access to Care Services' (2002) <https://webarchive.nationalarchives.gov.uk/20121205180615/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4019641.pdf> accessed 10 May 2019. It is the English equivalent to the Welsh Assembly Government document, Creating a Unified and Fair System for Assessing and Managing Care, discussed in Chapter 9.

¹⁰³ Zarb, 'The Road to Inclusion' (n60). This was the difficulty outlined by Mason in his discussion of the 'dream' coming up against 'reality'. See Chapter 6, Section 4.4.

away from any idea that one can look to the state for anything other than a minimal role...¹⁰⁴

And in Wales, the text authored by the Arfon Access Group stated (in relation to Welsh Government policy):

...it would seem that there are some misunderstandings regarding terms that we had thought were widely understood and unanimously agreed... there seems to have been concern expressed that the term 'independent' in 'independent living' refers to managing without support. This is very worrying indeed...¹⁰⁵

More recently activists have argued that social workers are using a 'bastardised' form of independent living that has turned its meaning "upside down".¹⁰⁶ In February 2019, the Reclaiming Our Futures Alliance stated:

The language of independent living has been appropriated by Government and public bodies to justify the cuts they are making. ... It is common practice for essential support to be removed from Disabled people through social care assessments under the justification of "helping" them to "improve their independence". Article 19 rights have thus been co-opted and subverted in order to facilitate the retrogression of Disabled people's rights.¹⁰⁷

The suggestion is, therefore, that the attempt to subvert the meaning of independence has itself been subverted. It is in this context that Morris recently argued that it might be prudent to abandon the language of 'independent living'.¹⁰⁸

¹⁰⁴ Jenny Morris, *Rethinking* (n2) 12.

¹⁰⁵ Arfon Access Group (n51) 1-2.

¹⁰⁶ John Pring, 'Conference Plans Fightback against Independent Living 'Catastrophe' (*Disability News Service*, 30 November 2017) <<https://www.disabilitynewsservice.com/conference-plans-fightback-against-independent-living-catastrophe/>> accessed 28 May 2018.

¹⁰⁷ Reclaiming Our Futures Alliance, 'Independent Living for the Future - Our Vision for a National Independent Living Support System: Summary' (2019) (*DPAC*, undated) <<https://dpac.uk.net/2019/02/motion-national-independent-living-support-service/nils-summary-doc-2/>> accessed 19 February 2019.

¹⁰⁸ See Chapter 2, Section 4.

The concept of independence also created particular problems in the political climate of austerity. Austerity is discussed in Chapter 3. In 2013 the New Economics Foundation identified independence as one of five values that are 'central to the austerity story' and stated:

Independence is a 'self-direction' value. It is associated with choice and freedom. The austerity story appeals to independence by making heroes of the strivers – people who don't rely on government to support them. It is a story of individualism, from the economy which we understand as a household, to citizens who decide how they want to live and whether to work hard and get a job.¹⁰⁹

In this context, the ideas of self-determination, choice and freedom had the potential to become inextricably re-connected to a narrative of independence-as-self-reliance combined with resources, placing the idea of independent living into ground that was even more difficult to navigate.

Various counter-narrative theorists have noted the risks that exist when a counter-narrative engages with, and on the ground occupied by, the master narrative.¹¹⁰ By using the language of independence, the disabled people's movement placed independent living into highly complex relationships of countering and compliance with a master narrative of dependence and the idea of self-reliance. The use of the language of independence in the counter-narrative, while powerful, was therefore problematic. The counter-narrative is simultaneously required to balance an explicit idea of a need for support with a concept that was generally connected with an *absence* of this need. This was a profoundly difficult task. Independence had significant potential to confuse or mean different things to different audiences, and it connected independent living to undesirable master narratives of self-sufficiency that were of particular value to audiences keen to reduce reliance on the welfare state.

¹⁰⁹ Carys Afoko and Daniel Vockins, *Framing the Economy: The Austerity Story* (New Economics Foundation 2013), citing Public Interest Research Centre (PIRC), *The Common Cause Handbook* (PIRC 2011).

¹¹⁰ See Chapter 4, section 7.2.

This difficulty created an area of particular risk for the effective take up of independent living in policy. Any attempt by the Welsh Government to translate independent living into the policy context would require an understanding of and an engagement with both the language of independence and its complex use within the movement. The DPM texts – particularly the dissenting texts – demonstrated that independence was already the site of a struggle for meaning and the construction and content of the counter-narrative. When transposed into the policy context, this struggle would take on new connotations. In the policy context, in which ambiguity is understood to be a useful means of smoothing over differences between different groups,¹¹¹ the language of independence would be a likely site of *both* genuine misunderstanding *and* the camouflage of distinction when independent living was discussed. How the idea of *independence* was used in the policy and legislative texts would be a critical indicator of both the Welsh Government’s understanding of, and its approaches to, the independent living counter-narrative.

4. Conclusion

This chapter has set the scene for the examination of the Welsh Government policy and legislative texts. It has set out the broad areas of adjacency and collision between independent living and the Welsh Government communitarian narrative, and has also raised a number of issues arising from the use of the language of independence by the disabled people’s movement. It notes that this is a critical area in which there was likely to be either confusion, or a struggle for meaning, or both. The final part of this thesis examines the Welsh Government’s approach to independent living and its component fragments of identity and agency, the construction of independent living, and the use of the language of independence in its policy and legislative texts.

¹¹¹ Catherine Needham, *Personalising Public Services: Understanding the Personalisation Narrative* (Policy Press 2011), particularly at 21-24. For discussion of the need to iron out differences between different groups in policy, and the role of counter-narrative in this process, see Chapter 4, Section 4.

Part III: Independent Living in Policy and Legislation in Wales

Chapter 9: The early policy documents

1. Introduction

This third and final part of the thesis examines the incorporation and treatment of independent living in Welsh Government policy and law, using the framework of adjacency and collision. The preceding part demonstrates that individuals and groups within the disabled people's movement developed independent living as a powerful activist counter-narrative. Independent living was capable of acting at both a personal and practical *and* a political and theoretical level and countering the double oppression of the deprivation of opportunity and the infiltrated self that arose from master narratives of deficit, otherness, dependency and care. It was a complex counter-narrative, required to resist these master narratives and 'reclaim' the meaning of independence; and to balance a profoundly important focus on the individual with the collectivist instincts of the disabled people's movement.

This thesis has already suggested that many activist counter-narratives will be optimally effective if they are accepted, endorsed and promulgated by state agencies and transmitted into policies and legislation.¹ The purpose of this part of the thesis is to establish the impact on independent living of its incorporation into Welsh Government policy and law on social care and disability, and the implications of this. It was inevitable that in the policy context the form of independent living would be adapted. The Welsh Government was itself engaged in a process of identity development through the creation of policy and legislation that repudiated certain values prevalent at Westminster which may have enabled certain aspects of independent living to thrive in the Anglo-British context.² In addition, it was required to manage scarce resources and the austerity agenda, appeal to Welsh public

¹ Chapter 4, section 4.

² Chapter 3, section 5.

opinion and to balance the principles of the disabled people's movement with other interests, including matters such as safeguarding duties. Where social care policy was involved, it was also required either to work within, or completely to overhaul, the system that it had inherited from Westminster on devolution. In Welsh Government policy, therefore, independent living would be required to function both within these constraints and within the Welsh Government's own value base.

Study of the relevant policy and law indicated that there had been a period of policy development in Wales during which there were particular opportunities for the incorporation of independent living. The history of policy on the relevant areas in Wales is set out in Chapter 3, section 6. It indicates that between 2012 and 2013 the Welsh Government developed a *Framework for Action on Independent Living* (the *Framework*) roughly contemporaneously with the earlier stages of the passage of the Social Services and Well-being (Wales) Bill, which reformed social care provision in Wales. These two developments were overseen by the same Minister³ and were to an extent connected, in that discussions around the *Framework* indicated that the forthcoming legislation would be a means of focusing social care on independent living.⁴ The *Framework* therefore brought independent living into the Welsh Government agenda at around the time that there was also a unique opportunity for a right to independent living to be incorporated into legislation on social care provision in the manner recommended by the Joint Committee on Human Rights in March 2012.⁵

For this reason, this part of the thesis is divided into three chapters. This short introductory chapter explores the treatment of the fragments of independent living in the Welsh Government's social care and disability policy output prior to this period of opportunity and before the Welsh Government demonstrated an awareness of the

³ Responsibility for the passage of the Social Services (Wales) Bill (later the Social Services and Well-being (Wales) Bill) through the Assembly was held by the Deputy Minister for Social Services, Gwenda Thomas AM. Responsibility for the consultation process on the *Framework for Action on Independent Living* was initially held by Gwenda Thomas AM and Jane Hutt AM, Minister for Finance and Leader of the House, who had given evidence to the Joint Committee investigation on the implementation of the right to independent living (see Chapter 2, section 4). The Framework was signed off by Gwenda Thomas AM in her ongoing capacity as Deputy Minister for Social Services and Jeff Cuthbert AM, Minister for Communities and Tackling Poverty.

⁴ See Chapter 10, Section 2.

⁵ See Chapter 2, section 4.

existence of independent living.⁶ The subsequent two chapters focus on the policy and legislation that formed this particular period of opportunity for the development of independent living in Wales. The *Framework* is considered in the following chapter, and the final chapter examines points that arise from the Social Services and Well-being (Wales) Act 2014, attendant legislation and explanatory documents.

2. An overview of the documents

Documents produced by the Welsh Government prior to the development of the *Framework* contained no obvious references to independent living in the form created by the disabled people's movement. The purpose of this chapter is therefore to examine the deployment of the fragments of independent living identified in Chapter 6 to establish whether and how these existed in Welsh Government policy prior to its stated acceptance of independent living.

A clear distinction was found between the earlier and later of these documents. Those developed prior to 2011 were noticeably more inclined towards the language, ideas and principles that the Welsh Government had inherited from Westminster than the two later documents, *Sustainable Social Services for Wales* ('*Sustainable Social Services*', 2011)⁷ and the *Consultation Document: Social Services Wales Bill* (the '*Consultation Document*', 2012).⁸ In particular, the two earliest documents in the dataset, *Creating a Unified and Fair System for Assessing and Managing Care* ('*CUFSAMC*', 2002)⁹ and the 2004 *Direct Payments Guidance*¹⁰ – both of which

⁶ See Chapter 3, section 6.2 for an explanation of how the Welsh Government became aware of the idea of independent living and acknowledged a need for policy in this area.

⁷ Welsh Assembly Government, 'Sustainable Social Services for Wales: A Framework for Action' (2011) <<http://gov.wales/docs/dhss/publications/110216frameworken.pdf>> accessed 23 February 2018.

⁸ Welsh Government, 'Consultation Document: Social Services (Wales) Bill' (2012) <<http://gov.wales/docs/dhss/consultation/120312consultationen.pdf>> accessed 23 February 2018.

⁹ Welsh Assembly Government and NHS Cymru, 'Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care' (2002) <<http://www.wales.nhs.uk/sitesplus/documents/829/WAG%20-%20Creating%20a%20Unified%20and%20Fair%20System%20for%20Assessing%20and%20Managi ng%20Care.PDF>> accessed 21 June 2019.

¹⁰ Welsh Assembly Government, 'Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance Wales 2004' (2004) <<http://www.wales.nhs.uk/documents/direct-payment-policy-e-merge.pdf>> accessed 21 June 2019.

formed legal guidance for local authorities on the practical workings of certain aspects of the social care system¹¹ – were heavily reliant on the equivalent Westminster documents produced for the English context.¹² This extended to the reproduction – sometimes with minor changes – of core ideas and large swathes of text.¹³ These early legal documents, therefore essentially cleaved to *Westminster* rather than Welsh principles. The later documents, in contrast, demonstrated a shift towards the principles and language that underpinned progressive universalism, and it was clear that – in policy texts at least – the Welsh Government was becoming more confident in asserting its own identity. This was clearly signalled by the statement in *Sustainable Social Services* that social care should be ‘based on our Welsh public services values’.¹⁴

The shift in policy principles between the earlier and later policy documents was demonstrated in various ways. Where the 2007 document *Fulfilled Lives, Supportive Communities* (*‘Fulfilled Lives’*) indicated a general acceptance of market principles within social services, and the use of private companies to deliver such services,¹⁵

¹¹ See Chapter 5, footnote 34.

¹² In 2002, the Department of Health produced ‘Fair Access to Care Services’ (‘FACS’). This sets out an eligibility regime that is essentially identical to that found in Chapter 5 of *CUFSAMC* (in which the relevant chapter is also entitled ‘Fair Access to Care Services’). The *Direct Payments Guidance* issued by the Welsh Government in 2004 is largely identical to the 2003 Direct Payments guidance issued by the Department of Health, although there are core differences in how these documents discuss personal assistance (see Section 2.2.4, below). The relevant Department of Health documents are: Department of Health, ‘Fair Access to Care Services’ (2002)

<https://webarchive.nationalarchives.gov.uk/20121205180615/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4019641.pdf> accessed 10 May 2019 and Department of Health, ‘Direct Payments Guidance Community Care, Services for Carers and Children’s Services (Direct Payments) Guidance England 2003’

<https://webarchive.nationalarchives.gov.uk/20071205205105/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4096246> accessed 30 July 2019.

¹³ Much of the 2004 Direct Payments Guidance was itself reproduced in subsequent guidance on direct payments by the Welsh Government. Welsh Assembly Government, ‘Direct Payments Guidance: Community Care, Services for Carers and Children’s Services (Direct Payments) (Wales) Guidance 2011’ (no longer available online). The 2007 document *Fulfilled Lives, Supportive Communities* (n15) contains a curious and unexplained reference to ‘other Whitehall departments’, which may be a civil service error that reflects the Welsh Office origins of much of the civil service in Wales. See Chapter 3, section 3.

¹⁴ WAG, ‘Sustainable Social Services’ (n7) para 1.2.

¹⁵ Welsh Assembly Government, ‘Fulfilled Lives, Supportive Communities: A Strategy for Social Services in Wales over the Next Decade’ (2007)

<<http://gov.wales/dhss/publications/socialcare/strategies/fulfilledlives/fulfilledlivese.pdf?lang=en>> accessed 23 February 2018. See, for example, ‘Adult social services are now mostly provided by private organisations and children’s social services increasingly so. Over the next decade local authorities are likely to remain the main commissioners of care. They need to take a much more active role individually and collectively in helping to shape the mixed market of private, public and

Sustainable Social Services rejected a market economy in care, and particularly the idea of personalisation,¹⁶ and created a focus on ‘social enterprise’ rather than companies run for profit.¹⁷ And while both *Fulfilled Lives* and *Sustainable Social Services* noted that social services were typically used by people in particular social groups,¹⁸ *Sustainable Social Services* also carried a strong message of mutuality and solidarity, positioning social services ‘at the heart of Welsh public life’¹⁹ and stating their value to all people.²⁰ The *Consultation Document* also developed a focus on universal access to support, suggesting that ‘social services’ should be more broadly defined and available to all rather than to those who have had a formal assessment of needs. Of particular relevance to this thesis were a movement in the later documents from the language of ‘choice’ to that of ‘voice’ and a shift away from the idea of independence. These are discussed below.

The chapter starts with a brief examination of the use of the phrase ‘independent living’ in these documents, before the analysis of the treatment of fragments of the counter-narrative across the whole texts and a study of how the language of ‘independence’ was understood and used. It closes with a discussion of the findings and their implications.

voluntary care. This means working within developed partnerships with independent and voluntary service providers recognising that commissioners and providers need each other’, para 4.25.

¹⁶ WAG, ‘Sustainable Social Services’ (n7). See, ‘We believe that the label “personalisation” has become too closely associated with a market-led model of consumer choice...’ para 3.16; and, ‘We recognise that private and independent providers play a crucial role in social care but do not believe that the market should determine priorities. We believe that, collectively, we should drive the market, not allow market choices to drive us. Social care must be delivered within a public service ethos and we will expect those who wish to be service providers to embrace this value base.’ para 3.11.

¹⁷ ‘We expect a much greater range of services to be run by citizens themselves, as service users, carers and as people delivering those services. Social care is ripe for the development of social enterprises. We will work with stakeholders to look at how the barriers to their development can be overcome.’ WAG, ‘Sustainable Social Services’ (n7) para 3.18.

¹⁸ In ‘Fulfilled Lives’ (WAG n15) these groups were characterised as ‘the vulnerable’ (Foreword, pages unnumbered), while ‘Sustainable Social Services’ (WAG n7) referred to ‘150,000 young, old and disabled people’ para 1.1.

¹⁹ WAG, ‘Sustainable Social Services’ (n7) para 1.1.

²⁰ WAG, ‘Sustainable Social Services’ (n7) para 2.3, ‘Public services are a critical part of that community and it is good news that they are there to support us. They are not an unfortunate necessity for a small group of people who for some reason are not able to resolve matters for themselves. We all need them, sometimes in significant measure, and sometimes in the background. They may be universal in nature or there to underpin us at times of significant difficulty. They are our right as citizens.’

3. The use of the phrase ‘independent living’

Across all of these documents, there were only eight substantive references to ‘independent living’,²¹ of which only one expressed ideas similar to the counter-narrative created by the disabled people’s movement. In these earlier documents, ‘independent living’ typically related to living arrangements that appeared to be equated with living alone, but which might also refer to ‘supported living’ arrangements, in which a person’s tenancy and support are separated.²²

For example:

Allowing sufficient time for effective transition planning for other life events such as an individual moving from the family home into independent living is equally important.²³

Certain references implied the idea of the transition of young people towards adulthood, for example:

²¹ There were also two references to the Independent Living Fund, both in paragraph 37 of the *Direct Payments Guidance*. WAG (n10).

²² The term ‘supported living’ is distinct from support provided in a registered residential home or hospital and can relate to any situation in which support is provided to a disabled person in their own home, by a provider who is not connected to the housing provider. It typically refers to situations in which disabled people (particularly people with learning disabilities) hold an individual or shared tenancy in purpose-built flats or houses, often owned by a social housing provider, with support provided by separate agencies. See, NHS ‘Supported Living Services’ (30 September 2018) <<https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/supported-living-services/>> accessed 21 February 2019. Supported living was originally devised as a means to enable disabled people – particularly those with learning disabilities – to have choice and control over their lives, although there are now concerns that in many cases this choice and control is lacking, and supported living is becoming a new form of institutionalism. For information on supported living as a means to enable choice and control see Peter Kinsella, ‘Supported Living: The Changing Paradigm – From Control to Freedom’ (*Family Advocacy*, 2001) <<https://www.family-advocacy.com/assets/Uploads/Downloadables/11288-Supported-Living-The-Changing-Paradigm.pdf>> accessed 8 July 2019; Alicia Wood and Rob Grieg, ‘Supported Living – Making the Move’ (*National Development Team for Inclusion*, 2010) <https://www.ndti.org.uk/uploads/files/Supported_Living_-_Making_the_Move,_May_2010.pdf> accessed 8 July 2019. For information on supported living and concerns about new forms of institutionalisation, see Rachel Fyson, Beth Tarleton and Linda Ward, ‘The impact of the Supporting People Programme on Adults with Learning Disabilities’ (*Joseph Rowntree Foundation* 2007) <<https://www.jrf.org.uk/report/impact-supporting-people-programme-adults-learning-disabilities>> accessed 8 July 2019.

²³ Welsh Assembly Government, ‘Statement on Policy & Practice for Adults with a Learning Disability’ (2007) <<http://gov.wales/docs/dhss/publications/100126policyen.pdf>> accessed 23 February 2018, para 6.3. See also, ‘Direct payments may also be used to enable people who are living in care homes to have temporary access to direct payments to try out independent living arrangements before making a commitment to moving out of their care home’. WAG, ‘Direct Payments Guidance’ (n10) para 79. Overall, there were three such references in the earlier documents.

There is significant evidence of the dip in service provision for disabled young people when they transfer to adult services and begin their preparations for independent living.²⁴

The single reference that was connected to the narrative developed by the disabled people's movement occurred in the preface to the 2007 *Statement on Policy & Practice for Adults with a Learning Disability* ('the Learning Disability Statement'). The preface was drafted by All Wales People First and stated:

Accommodation and Independent Living - Having a place and a life of your own. Many of us see this as our main goal in life. Having a home that you can call your own can put you at the heart of a community. If we are going to make a success of living in our own homes we need to be able to choose from a range of good housing in suitable locations. And we need the right support that fits people's needs. These key points show that by building on skills and by working with a wide range of people, we can achieve better inclusion in society. We can build bridges to work with the different services and businesses, and really live as valued citizens, as part of our local neighbourhood and as part of the wider community.²⁵

While this extract was particularly associated with housing options, it contained a strong sense of a meaningful and valued life, community living and inclusion, and hinted at self-determination.

There was also a reference to centres for independent living in the 2004 *Direct Payments Guidance*,²⁶ although elsewhere in the document 'independent living' related to the ideas akin to supported living and transition to adulthood.²⁷ Indeed, an allusion to 'the spirit of independent living' that appeared to refer to the counter-narrative of the disabled people's movement was removed from an early draft of the

²⁴ WG, 'Consultation Document' (n8) para 6.2.1.

²⁵ WAG, 'Learning Disability Statement' (n23) 7.

²⁶ WAG (n10) para 26.

²⁷ In this, the Guidance was very similar to the equivalent Department of Health guidance. Department of Health (n12).

guidance following consultation. The final document referred instead to requirements to 'enable and sustain the individual's *independence*' (emphasis added).²⁸

Similarly, there were no references to the UNCRPD in any of these documents, although there were references to the UN Convention on the Rights of the Child (UNCRC) in *Fulfilled Lives, Sustainable Social Services* and the *Consultation Document*, and to the UN Principles for Older Persons in the first two of these documents.²⁹ As *Sustainable Social Services for Wales* was published after the UK became a signatory to the CRPD in July 2009, it appeared that there was on the part of the Welsh Government either a lack of awareness of its existence or a reluctance specifically or visibly to highlight or commit to its content in this document and the later *Consultation Document*.

4. Fragments of the independent living counter-narrative

Despite the lack of discussion of the independent living counter-narrative in the documents prior to the *Framework*, certain of the fragments of independent living did appear. The treatment of these fragments was fundamentally different in the *Learning Disability Statement* than the other documents in the WG dataset, and this document is therefore considered separately at the end of this section. The numbers of references to the fragments in all the Welsh Government documents are provided in Appendix 8.

²⁸ Paragraph 53. The end of paragraph 53 in the *draft* direct payments guidance read: 'Before direct payments begin, authorities should satisfy themselves that the relationship between the individual and the agent will honour the spirit of independent living'. Various agencies including local authorities requested clarification of the meaning of this phrase. In the final document, the final sentence was amended to, 'Before direct payments begin, authorities should satisfy themselves that the relationship between the individual and the agent will enable and sustain the individual's independence'. In the equivalent Department of Health document, this phrase remained unaltered, continuing to refer to the 'spirit of independent living'. See, Department of Health, n12 para 51). The draft guidance was sent by the Welsh Assembly Government to local authorities and other relevant organisations on 23 January 2004. It is not available online, and was sent to the author by e-mail from the Welsh Government (22 June 2018).

²⁹ It will be remembered that the UNCRC is partially incorporated into domestic legislation in Wales. See Chapter 8, Section 2. The UN Principles for Older Persons are, however, not a legally binding document. The UN Principles for Older Persons were adopted by the UN General Assembly on 16 December 1991. They are available at <<https://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx>> accessed 30 July 2019.

4.1 Fragments of personal agency

Fragments of the personal agency narrative were strongly found in these documents, although this was partly accounted for by large numbers of references to both these fragments in the 2004 *Direct Payments Guidance*. Choice and, to a lesser extent, control were frequently referenced and were prioritised, although the focus on choice was lessened in the later texts.³⁰ The earliest document in the dataset, *CUFSAMC* (2002), comprised legally binding guidance on local authorities in relation to assessments and eligibility for adult social care support.³¹ This document shared content with the equivalent document issued by the Department of Health for use in the English context.³² In line with that document, *CUFSAMC* stated that the core criterion in assessing eligibility was that of a person's 'risks to independence' and established 'autonomy' as one of four 'key factors of independence'.³³ Autonomy was defined as:

'the control a person has over their immediate situation and the extent to which they are able to make and act on informed choices'.³⁴

From this document onwards, individual control was cited in every text as a core principle. In *Fulfilled Lives* control was paired with 'choice' as a core principle for social care:

Whatever their difficulty or impairment, people **should be supported to have control over the life they wish to live**.³⁵ (Original emphasis).

³⁰ Choice and control were referenced more than any other fragments. Including the *Learning Disability Statement*, there were 83 references to choice. Of these, thirty eight were found in the *Direct Payments Guidance* and 16 in the *Learning Disability Statement*. There were 62 references to control, of which 13 were in the *Direct Payments Guidance* and three were in the *Learning Disability Statement*. Many of the references to choice in the *Direct Payments Guidance* were connected to the management of support, including the choice to receive (or to stop receiving) direct payments.

³¹ The document was issued under section 7(1) of the Local Authority Social Services Act 1970 and therefore formed guidance that local authorities were legally obliged to follow. See Chapter 5, section 4.3.

³² Department of Health, (n12).

³³ WAG (n9) para 5.10. For further discussion see section 3, below.

³⁴ *Ibid* para 5.10.

³⁵ WAG (n15) para 1.8.

Sustainable Social Services expressed a need for a shift of control from local authorities, or ‘services’, to individuals. This was understood to be a change in the underlying narrative of social care:

... we believe that a model of social work rooted in assessment and care management is not one that is fit for the next stage of development...the concept of “care management” is outmoded - conveying a sense of control by the service, not by the citizen.³⁶

As noted above, in *Sustainable Social Services* and the *Consultation Document*, the language of *choice* and control gave way to that of *voice* and control.³⁷ In both these documents, ‘a strong voice and real control’ formed a core principle for social care which was repeated consistently,³⁸ in a manner that was similar to the ‘mantra’ of ‘choice and control’ that was definitional to independent living. The idea of choice was less commonly articulated in these texts, and was indeed rejected in *Sustainable Social Services*:

We believe that the label “personalisation” has become too closely associated with a market-led model of consumer choice, but we are taken by the Commission’s approach to stronger citizen control.³⁹

The distinction between voice and choice in the texts was, however, not always clear. For example:

³⁶ WAG (n7) para 3.59. See also para 3.13, ‘At the heart of this will be a new balance in our relationship with service users themselves. This way we will strike a new accord in our national, regional and local relationships and in our relationship with those who rely on social services in Wales.’

³⁷ The word ‘voice’ did not appear at all in either *CUFSAMC* (WAG n9) or the *Direct Payments Guidance* (WAG n10), which borrowed extensively from their English counterparts.

³⁸ This was sometimes phrased as ‘a stronger voice and real control’ (emphasis added). Chapter 2 of the *Consultation Document* (n8), which outlined the core elements of assessment and planning for social care, was headed ‘A stronger voice and real control’.

³⁹ WAG, ‘Sustainable Social Services’ (n7) para 3.16. The ‘Commission’ is the Independent Commission on Social Services in Wales, the report of which, ‘From Vision to Action’ was published in November 2010. Independent Commission on Social Services in Wales, ‘From Vision to Action’ (2010) <<https://www.valeofglamorgan.gov.uk/Documents/Our%20Council/Achieving%20our%20vision/Independent-Commission-on-Social-Services,-November-2010.pdf>> accessed 29 July 2019.

The legislation will also seek to provide individuals with a stronger voice and real control. Our proposals ... will require those assessments to be carried out in a way that focuses on the outcomes *that people themselves are seeking* (emphasis added).⁴⁰

Similarly, it was not clear how control could be embraced and placed as a central element of policy without individual choice also being incorporated and activated. The connection between these ideas is explored in Chapter 6, section 4.1.1, where it is suggested that control enables choice by default.

There was little *content* created for any of these ideas. With the exception of the *Learning Disability Statement* (see further below), there was limited sense of what choice, control, or voice would consist of, or what life would look like for those who had them. However, where support or services were under discussion, choice, voice and control were frequently compromised and partial. For example (emphases added):

...people who need services will have a far **greater** say over what they need and how it is provided.⁴¹

We will ensure that service users and carers have a much **stronger** voice and **greater** control over their services.⁴²

In addition, the public sector itself was seen to be capable of acting as the voice of those using services:

The intention is to create a single stronger voice for social services ... and, through that, for those who use the service.⁴³

⁴⁰ WG, 'Consultation Document' (n8) 6.

⁴¹ WAG, 'Fulfilled Lives' (n15) Foreword (pages unnumbered).

⁴² WAG, 'Sustainable Social Services' (n7) 3.

⁴³ WAG, 'Fulfilled Lives' (n15) para 4.19. The same idea was found in *Sustainable Social Services* (WAG n7), which stated: 'The statutory role of the Director of Social Services is essential in ... providing a corporate voice for disadvantaged groups in society' (para 3.3); and the *Consultation Document* (WG n8) para 3.3.3.

4.2 Fragments of social agency

The core elements of social agency were also found with these documents, including inclusion, participation, community living and having an active life.⁴⁴ Numerically, communities were strongly referenced.⁴⁵ Communities were discussed in various ways, with references, for example, to the role of communities in supporting individuals,⁴⁶ and the role of social services in promoting 'community safety'.⁴⁷ Inclusion was an important theme. In *Fulfilled Lives*, social inclusion was set out as a core outcome of social services.⁴⁸ Similarly, *CUFSAMC* stated:

Social and health care services provided for vulnerable adults therefore must aim to promote maximum independence and to support community integration. These are features of the developments to tackle social exclusion, and to promote and maintain health and normal patterns of living whenever possible.⁴⁹

In the *Consultation Document*, the notion of an active, meaningful life was connected to the idea of wellbeing:

⁴⁴ Including references in the *Learning Disability Statement*, there were 68 references to communities or community life, 47 to inclusion, 44 to having an active and meaningful life and 20 to participation. There were also 21 to employment.

⁴⁵ There were 68 references to communities across these documents. When the high number of references to both choice and control in the *Direct Payments Guidance* was taken into account, this was the highest number of references to any of the fragments of independent living that related to outcomes. However, this included references to communities that went beyond individuals having a community life. There were 25 references to community life or communities in the *Learning Disability Strategy*.

⁴⁶ See, for example, '[t]he answer is not a return to the "prevention role" for social services, but recognition that the whole local authority has a responsibility for leading community services and promoting community wellbeing and that it should galvanize the communities' own commitment to enable its citizens to play a full part'. WAG, 'Sustainable Social Services' (n7) para 3.22; and, '[w]e believe therefore that social services and social care must act in ways that ...enable us to make a full contribution to the community and draw on it to support us (ibid para 2.4). The idea of communities supporting individuals is most obviously seen in the title 'Fulfilled Lives, Supportive Communities' (WAG n15).

⁴⁷ See, for example, WAG, 'Fulfilled Lives' (n15) para 1.3; WAG, 'Sustainable Social Services' (n7) para 3.3.

⁴⁸ 'Social services and social care in Wales play a vital part in the lives of many of the citizens of Wales of all ages. They: **promote social inclusion and independence**, advocating on people's behalf, asserting their rights and supporting them to achieve their potential and to be active citizens.' Para 1.4, original emphasis.

⁴⁹ 2002, CUFSAMC 1.9. See also: 'We will need social services to be active champions for the needs of the vulnerable and promote their inclusion in local communities'. 2007, FLSC, Foreword. And:

Central to the Welsh Government's model of Sustainability is the concept of 'wellbeing'. The Bill will have a positive impact on the wellbeing of services users and their carers, by ensuring that: their basic needs are met and they are supported to lead full lives that have a sense of purpose; and that they feel able to reach personal goals and participate in society.⁵⁰

There was significant discussion of wellbeing in *Fulfilled Lives*, *Sustainable Social Services* and the *Consultation Document*.⁵¹ Across the dataset, wellbeing was related to individuals using support, carers and communities but was typically vague and imprecise. In the *Consultation Document* the intention to create a new wellbeing duty under the forthcoming legislation was discussed. This required more specificity, and a 'working definition' of wellbeing was given.⁵²

Despite these references to wellbeing and to elements of social agency, overall there was a limited sense of ambition for individuals using social care and other social services and rarely any sense of the lives that could be achieved by those using social care support or the social roles that these individuals did or could perform. Indeed, the extract cited immediately above demonstrates a somewhat ambivalent expression of these ideas, with its references to 'basic needs' and lives that have 'a sense of purpose'. There was no rich discussion of individuals using social care or other social services as, for example, parents, employees, friends, neighbours, or as users of local services such as shops, banks, pubs, restaurants or sports or leisure facilities. While there were indications that people had particular expectations of services and could lead 'fulfilled' lives, there was no accompanying sense that

⁵⁰ Welsh Government, 'Consultation Document' (n8) para 7.9.

⁵¹ There were 12 references to wellbeing in *Fulfilled Lives* (n15) and 18 in the *Consultation Document* (n8) including a long extract of many paragraphs entitled 'Wellbeing of people in need: What are the main issues?' There were four in *Sustainable Social Services for Wales* (n7), which also included a section entitled: 'Safeguarding and promoting the wellbeing of citizens'. Wellbeing was a weaker theme in the documents that were 'inherited' from Westminster. There were two references in the *Direct Payments Guidance* (n12) and none in *CUFSA MC* (n12). There were three in the *Learning Disability Statement* (n23).

⁵² This encompassed: '(a) physical and mental health and emotional wellbeing; (b) protection from harm and neglect; (c) education, training and recreation; (d) the contribution made by them to society; (e) securing their rights; and (f) social and economic wellbeing'. WG, 'Consultation Document' (n8) para 1.1.7. Discussion on the final elements of the wellbeing duty in the Social Services and Well-being (Wales) Act 2014 and their implications for independent living is found in Chapter 11.

individuals might also have high expectations of their own lives or of what ‘fulfilment’ would mean. In contrast, there were various references to individuals as ‘vulnerable’ rather than active,⁵³ or – as seen in one of the extracts cited above – to ‘normality’. These drew the identities of disabled people back into the master narratives identified by the movement and created a sense of deviance for those in need of assistance.

4.3 Equality and rights

References to rights were also found in these documents.⁵⁴ These were typically broad and general references to unspecified rights, including various references to ‘rights-based approaches’ to support or services. There were particular references to children’s rights, underpinned by the Welsh Government’s legal commitment to the UNCRC.⁵⁵ Particularly in the *Consultation Document*, references to rights also included various references to entitlements created by legal duties upon local authorities, such as a right to information or to an assessment.

However, one fragment of the independent living counter-narrative that was scarcely mentioned across any of these documents was equality. Other than a reference in the 2004 *Direct Payments Guidance* (relating to children),⁵⁶ the only *substantive* reference to equality came in a statement in *Fulfilled Lives* that also referenced the social model. This stated that the Welsh Government vision for social care services was:

⁵³ WAG, ‘CUFSAMC’ (n9), various paras; WAG, ‘Direct Payments Guidance’ (n10) para 111; WAG, ‘Learning Disability Statement’ (n23) paras 3.8, 5.1 and 5.9; WAG, ‘Fulfilled Lives’ (n15) various paras; WG, ‘Consultation Document’ (n8) various paras, including one reference that acknowledged the distaste for the use of this term (para 4.3.7).

⁵⁴ There were 41 references to rights or entitlements, including entitlements relevant to other groups, such as carers. This included 12 references in the *Learning Disability Strategy*.

⁵⁵ For example, WAG, ‘Sustainable Social Services’ para 3.80; WG, ‘Consultation Document’ (n8) 6.

⁵⁶ ‘Parents should be encouraged and supported to use direct payments with a view to enabling their disabled children to access the same kinds of opportunities and activities as their non-disabled peers’. WAG, ‘Direct Payments Guidance’ (n10) para 122,

....firmly rooted in both the social model of disability, and in a rights-based approach....The social model of disability promotes rights, equality and choice for all disabled people.⁵⁷

This reference to equality was conspicuously brief and open in its meaning.⁵⁸ As with the elements of social agency discussed above, there was no sense of what equality might mean for disabled people and how it would impact on a person's life.

4.4 Enablers of the fragments of independent living

Direct payments had a unique position in these texts. Across the documents they had a particularly strong connection with fragments of independent living. The *Direct Payments Guidance*, particularly extracts that were lifted from the equivalent Department of Health guidance, contained many of these fragments. For example:

Direct payments ... promote independence, choice and inclusion by enabling people to purchase the assistance or services that the council would otherwise provide in order to live in their own homes, be fully involved in family and community life, and to engage in work, education and leisure.⁵⁹

As this quote illustrates, and as discussed above, the language of *independence* rather than independent living was preferred.

Direct payments were particularly strongly connected with the fragments of personal agency. In the *Direct Payments Guidance*, the themes of choice and control were far more frequently and strongly articulated than in any other document, with these themes more closely woven into the text and frequently appearing as implicit as well

⁵⁷ WAG, 'Fulfilled Lives' para 1.9. None of the other documents cited the social model.

⁵⁸ There were other references to equality, but these were either references to equality of access to or within services, or duties under equalities legislation. Across the documents as a whole, there were 43 references to equality, of which 23 were in the *Learning Disability Statement* and 15 related to equality of access to services and five to equalities legislation.

⁵⁹ WAG, 'Direct Payments Guidance' (n10) para 9. This is reproduced directly from paragraph 7 in the equivalent Department of Health guidance (n12).

as explicit ideas. Even in this text, however, it was indicated that both choice and control ultimately remained with the local authority:

The authority is not obliged to fund the particular costs associated with the individual's preferred method of securing the service if... the service can in fact be secured more cost effectively (but still to the required standard) in another way.⁶⁰

Similarly, throughout the texts, direct payments were positioned as the core means to enable choice and control for people using social care support. For example:

For some people, control means managing their service themselves. Direct payments are an important tool for greater control for some people.⁶¹

This was particularly apparent in the 2012 *Consultation Document*. In addition, in the section of this document that focused on direct payments the theme of voice and control – which was otherwise prevalent throughout – gave way to that of *choice* and control.⁶² The short 'definition' of independent living devised by Disability Wales was also reproduced in this section,⁶³ although neither this connection nor independent living itself were directly mentioned.

Personal assistance was not mentioned in the documents, other than in the *Direct Payments Guidance*, although it remained scarcely referenced in this text.⁶⁴ This was in direct contrast to the equivalent Department of Health document, which contained a large number of examples of direct payment use which related to the purchasing of personal assistance, all of which were removed in the Welsh

⁶⁰ Ibid para 86. This statement is lifted directly from the Department of Health guidance (n12), in which it appears in para 84.

⁶¹ WAG, 'Sustainable Social Services' (n7) para 3.17. See also, 'The purpose of Direct Payments is to give recipients greater control over their own life'. WAG, 'Learning Disability Statement' para 7.12.

⁶² 'Voice' was referred to only once in this section, which referred directly to the Welsh Government 'principles for social care'. Otherwise, the idea of 'choice' was present.

⁶³ The 'definition' given by Disability Wales was: 'Independent living enables us as disabled people to achieve our own goals and live our lives in the way that we choose for ourselves'. For discussion of this short definition, see Chapter 7, section 3.

⁶⁴ There were eight references in this relatively long document (n10). There was also reference to disabled people as employers, but the link with personal assistance was not clearly made. See in particular paras 101 to 104.

Government text. More typically, the Welsh guidance referred to individuals using direct payments to purchase 'services'.⁶⁵

In terms of the fragments of independent living, the texts referred to various enablers including telecare⁶⁶, information,⁶⁷ the forthcoming legislation,⁶⁸ user involvement,⁶⁹ co-production,⁷⁰ and communities.⁷¹ By far the most commonly referenced enabler throughout the texts was 'services',⁷² and the *Consultation Document* suggested that the meaning of 'services' should be expanded to include universal services available to all people.⁷³ The language of 'support', 'help', or 'assistance' was also used, but these were outweighed by references to services and to 'care'.⁷⁴ Matters of importance to disabled activists, such as access and peer support were present in the texts, although not strongly discussed.⁷⁵

⁶⁵ The equivalent Department of Health document (n12) also made numerous references to direct payments purchasing 'services', but balanced these with the examples of personal assistance.

⁶⁶ Telecare is technology installed in a person's home that enables the individual to be in contact with people if necessary, and/or which remotely monitors activity and movement to identify, for example, if someone has fallen or remained inactive for a significant period. Paragraph 4.39 of *Fulfilled Lives* (n15) states: 'However telecare - remote monitoring of citizens' wellbeing, with early identification of needs - can offer more effective services that help users to keep control of their lives.'

⁶⁷ There were various references to people making informed choices or decisions. There were also occasional references to the need for information for a person to have control over their lives. For example, 'In order to exercise control and have a strong voice, people need to be able to access information about services'. WG, 'Consultation Document' (n8) para 2.1.2.

⁶⁸ For example, 'This Bill will give people a strong voice and real control.' WG, 'Consultation Document' (n8) p3.

⁶⁹ There were a handful of references to the need to involve individuals, particularly in relation to choice over services. For example, 'If it is not obvious initially how an individual communicates choices, care should be taken to involve in the process people who know the service user well and understand how they express their preferences'. WAG, 'Direct Payments Guidance' (n10) para 64.

⁷⁰ There were two references to co-production in relation to control over services, one in 'Sustainable Social Services' (n7 para 3.58); and one in the 'Consultation Document' (n8 para 2.4.9).

⁷¹ For example, 'Our communities need to develop so that they support the most vulnerable and troubled families'. WAG, 'Fulfilled Lives' (n15) para 3.15.

⁷² In the coding process, coding to 'services' was eventually discontinued, as the number of references meant that huge swathes of the documents were being coded to this theme. Across all the documents there were in excess of 700 references to services.

⁷³ The aim here was to enable people to receive support at an earlier stage and reduce the need for assessments and social care provision. See further Chapter 11.

⁷⁴ The coding of 'care' was also discontinued. Across the documents there were over 1,000 references to 'care', including the frequently used phrase 'care services'. The *Consultation Document* made various allusions to 'care and support', which is the phrase that has been adopted in Wales and England to refer to support received through the social care system. This phrase was used in the Law Commission report on Social Care discussed in Chapter 3, section 6. See, Law Commission, *Adult Social Care* (Law Com No 326, 2011).

⁷⁵ Access to services, however, was commonly cited. Across the documents there were 64 such references. Other forms of access were only mentioned in the *Learning Disability Statement* (n23, two references). Peer support was referenced nine times, with the majority of these in the *Direct Payments Guidance* (n10).

One enabler that was conspicuously lacking in the texts, despite the Welsh Government's stated interest in it, was that of citizen-directed support (CDS) – the distinctively Welsh approach to social care that was intended to merge the values of individual agency and community development.⁷⁶ However, citizen-centred support was expressed as a priority in all the documents other than the *Direct Payments Guidance*, with multiple references to the need for support to be 'person-centred' or 'individually tailored'.⁷⁷ This implied a lesser control for the citizen than CDS, and this control was diminished further by indications that individuals would have an *involvement* in the assessment and planning processes, rather than management of it:

...assessment should always be person-centred. This means ensuring that the person's views and wishes *shape* the assessment process (emphasis added).⁷⁸

This switch of language from CDS to 'citizen-centred support' was noted and challenged by the Arfon Access Group in its response to the consultation on the Social Services (Wales) Bill.⁷⁹

⁷⁶ See Chapter 7 for an explanation and discussion of CDS.

⁷⁷ Across all the documents there were 60 references to person-centred or individualised support. These included a handful of references of 'self-directed' support. The emphasis on person-centred planning in CUFSAMC was particularly relevant as that document set out the assessment and planning processes for social care. WAG, 'CUFSAMC' (n9) Foreword and paras 2.8 – 2.10. In the other documents, see: WAG, 'Learning Disability Strategy' (n23) Preface and Chapter 6; WAG, 'Fulfilled Lives' (n15) paras 3.6, 3.14, 3.15, 4.1 and 4.2; WAG, 'Sustainable Social Services' (n7) paras 3.15-3.20; WG, 'Consultation Document' (n8) Foreword and para 2.4.9. The *Direct Payments Guidance* (WAG n10) focused more on the use of direct payments following assessment.

⁷⁸ WAG, 'CUFSAMC' (n9) para 2.8. See also, 'It is particularly important for people living with long-term conditions be (sic) involved in making choices, decisions and actions about their care. WAG, 'Sustainable Social Services' (n7) para 3.16. There were 25 such references in the documents.

⁷⁹ This states, "The third area where confusion seems to have seeped in is the concept of Citizen Directed Support. Again we thought that consensus had been broadly achieved here and we were surprised and disappointed that after a great deal of work on the consultation paper on CDS by members of WACDS and an apparently firm commitment to CDS in the Welsh Local Government Implementation Plan, the paper had somehow slipped beneath the surface and the language in the Bill has shifted back a decade or two and now talks about 'citizen-centred' instead of citizen directed." Letter from Vin West on behalf of Arfon Access Group / Grwp Mynediad Arfon to Sarah Beasley, Clerk to Health & Social Care Committee, (15 March 2013) (accepted as a response to the consultation on the Social Services and Well-being Wales Bill) <www.senedd.assembly.wales/documents/s15313/SSW%2043%20Arfon%20Access%20Group.pdf> accessed 2 January 2017. See Chapter 7, Section 4.4.

However, there was also discussion, particularly in the *Consultation Document*, of the desire to develop:

a model of self-directed support that is consistent with our principles for social care and ensures that service users and their carers have a much stronger voice and control over their services.

This new model was specifically connected to direct payments and was stated to be:

...not an approach driven by the market or by consumerism but by a wish to enable people to achieve their goals and live their lives in the way they choose for themselves.

The ideas of co-production and the use of cooperatives as a business model for the provision of support were also present:

Service users and carers, including children and young people, need a stronger voice in service design and evaluation. **We expect a much greater range of services to be run by citizens themselves, as service users, carers and as people delivering those services**⁸⁰ (original emphasis).

4.5 The Learning Disability Statement

The *Learning Disability Statement* was a unique document among these earlier texts. In addition to being the only document to use the phrase 'independent living' in a manner that echoed the counter-narrative devised by the disabled people's movement, it was also the only document to have a vivid focus on the counter-narrative's component fragments. This document, which was legally binding and set out a series of broad policy expectations,⁸¹ was richly infused with the narratives of

⁸⁰ WAG, 'Sustainable Social Services' (n7) para 3.18.

⁸¹ Like *CUFSA* and the *Direct Payments Guidance*, the *Learning Disability Statement* was issued under section 7(1) of the Local Authority Social Services Act 1970 and therefore formed guidance that local authorities were legally obliged to follow (see Chapter 5, section 4.3). It built on an earlier Welsh Assembly Government strategy document, also issued under section 7(1). Welsh Assembly

social and personal agency and the matter of equality. Particularly in Section 7, entitled 'Leading an ordinary life', it strongly advocated for individuals with a learning disability to live in local communities, with meaningful life opportunities equal to non-disabled people, and presented them as citizens, employees, friends and parents, with the capacity to make their own choices and determine their own lives.

...an individual's requirements may typically change over time including, for example, when an individual with a learning disability becomes a parent. ... an authority's goal should be for people with learning disabilities to have a genuine opportunity to live as others of the same age and play a full part in the society in which they live... [with] the opportunities and support required for individuals to follow the lifestyle choices which maximise their well-being and personal development.

There were also references to the need to remove damaging narratives around people with learning disabilities:

...it is of course important that services ... do not themselves perpetuate negative perceptions of people with a disability. Everything should be done to make sure that people are represented as full citizens with rights and expectations which are typical for others of the same age. ...Care needs to be taken when referring to people's genuine needs for guidance, support and particular treatment to avoid the impression that individuals are incapable of exercising choice and control, or of making a positive contribution to society.⁸²

This document followed two earlier policy texts relating to people with learning disabilities that are generally considered to be progressive.⁸³ Both were issued by

Government, 'Learning Disability Strategy: Section 7 Guidance on Service Principles and Service Responses' (2004) (no longer available online).

⁸² WAG, 'Learning Disability Statement' (n23) para 7.7. There was also a reference to the need for a cultural shift in the *Direct Payments Guidance* (n10), which stated (at para 12): 'For some staff/professionals, direct payments may require a significant change from current ways of working with people needing services. However, those staff who have made the 'cultural leap' have discovered that they experience the great satisfaction that comes from expanding individuals' lifestyle choices.'

⁸³ Learning Disability Advisory Group, 'Fulfilling the Promises: Report to the National Assembly for Wales' (2001)

<<http://www.assembly.wales/Laid%20Documents/The%20Learning%20Disability%20Advisory%20Gro>

the Welsh Office under Conservative governments – in 1983⁸⁴ and 1994⁸⁵ – with the second reaffirmed by the Welsh Assembly Government in 2002.⁸⁶ The main principles of the 1994 document, cited at paragraph 7.2 of the *Learning Disability Statement*, incorporate many of the elements that were later articulated in Article 19 of the UNCRPD.⁸⁷

5. The language of ‘independence’

The difference in these documents between the earlier ones, which were largely aligned with the equivalent texts produced at Westminster, and the later ones, in which the Welsh Government was more effectively asserting its own policy identity, is discussed above. This shift was also seen in the approach to the concept of independence. In the first four documents, ‘independence’ was situated as a core priority. As noted above, *CUFSAMC* positioned independence alongside social inclusion as one of four key aims of social services in Wales and placed independence at the heart of eligibility decision-making in social care.⁸⁸ In *CUFSAMC* four key elements of independence were identified. These were:

up.%20Report%20to%20the%20National%20Assembly%20for%20Wales%20Fulfilling%20the%20Pr omises.%20Propo-17102001-24340/bus-GUIDE-3BD5365D0001C81F0000500700000000- English.pdf> accessed 30 July 2019.

⁸⁴ Welsh Office, 'All Wales Strategy for the Development of Services for Mentally Handicapped People' (Welsh Office 1983).

⁸⁵ Welsh Office, 'All Wales Strategy for the Development of Services for Mentally Handicapped People (Revised Guidance)' (Welsh Office 1994).

⁸⁶ WAG, 'Learning Disability Strategy (n23) para 1.1.

⁸⁷ Para 7.2 reads: 'The 1994 Revised Guidance had a number of clear objectives: • Provision of a range of accommodation so that people with learning disabilities have as much freedom as anyone else to choose where they live and with whom they live, and a level of support which enables them to continue to live in the community. • Help to obtain a real job for most adults and support to help them keep it - all adults who are able to work should have the opportunity of paid employment alongside other members of the community. • Help and support to become part of the community and to take part in leisure activities among other people. • Access to the same healthcare as others living in the community, with additional support to meet special health needs.' WAG, 'Learning Disability Statement' (n23).

⁸⁸ Social inclusion was given as the first of these four aims, with the aim defined as: 'To contribute towards securing an inclusive society in which people can lead productive and meaningful lives'. The aim of 'independence' was defined as 'To support individuals and families towards greater independence'. The other two core aims were 'responsiveness' (defined as 'provid[ing] services which are responsive to individual needs and choice) and 'carers' (defined as 'recognis[ing] and support[ing] carers of all ages in their role in caring for vulnerable people'). WAG, 'CUFSAMC' (n9) para 1.6.

Autonomy (the control of the person over their situation and the extent to which they can make and act on choices);

Health and safety (risks to the person's mental and physical health and their and others' safety, including freedom from harm, abuse and neglect);

Managing daily routines (the ability of a person to meet their own personal and domestic needs and daily routines and to look after family members or others);

Involvement: (a person's involvement in work, education, leisure, family life, social networks and community activities, and their social roles and responsibilities including parenting and caring).⁸⁹

As this document was legally binding upon local authorities, this effectively formed a legal definition of 'independence' in the context of social care in Wales. *CUFSAMC* therefore – in line with the equivalent guidance issued by the Department of Health in Westminster – placed a definition of independence at the heart of social care in Wales that incorporated *both* the ideas of self-determination and self-reliance that were distinguished and separated by the disabled people's movement, although it was explicitly stated that 'service users' often prioritised autonomy.⁹⁰ It is remarkable that this definition also includes a reference to inclusion and 'involvement' – a matter which has no connection to dictionary definitions of 'independence'. It appeared therefore to be strongly influenced by the content of independent living, to which the Westminster government was then becoming more attuned.⁹¹ If this is the case, the

⁸⁹ Ibid, paras 2.36 and 5.10. These four elements closely echoed those in the equivalent document issued by the Department of Health (n12 para 40)..

⁹⁰ The document states that none of the four elements should take priority, but notes that 'service users often give autonomy a higher priority than the others' (para 5.11).

⁹¹ The Department of Health document (n12) is dated 28 May 2002. The first reference to independence in a construction that appears to recognise the content of independent living identified by the author in a Westminster policy document occurs in the 2001 document, 'Valuing People'. This states: 'While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.' Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Cm 5086, 2001) 23.

references to the prioritisation of autonomy by 'service users' is notably weak, given the overwhelming focus on this in the counter-narrative of independent living.

Independence was subsequently prioritised in the *Direct Payments Guidance*,⁹² the *Learning Disability Statement*⁹³ and *Fulfilled Lives*.⁹⁴ In each text it was discussed as a core intended outcome for individuals using social care support and other social services. However, a significant shift appeared in the 2011 white paper, *Sustainable Social Services for Wales*, which stated:

We look *not* for independence and separateness, but for interdependency with those around us.⁹⁵ (Emphasis added. The 'we' in this sentence referred unequivocally to all citizens.⁹⁶)

This statement was unique in being the only negative consideration of independence in any of the Welsh Government documents. This document was also unique in that it contained almost no other subsequent references to independence.⁹⁷ The approach to independence in the subsequent *Consultation Document* on the legislation to implement the principles of *Sustainable Social Services* was conflicted. Here independence was not stated as a priority, but did come to the fore as a core aim of services in the section on direct payments.⁹⁸

In each of these documents relevant references to independence were coded as one of: 'self-determination', 'self-reliance', 'ambiguous', or 'containing both these ideas'.

⁹² WAG, 'Direct Payments Guidance' (n10) 'Foreword and paras 9 and 14, among others.

⁹³ WAG, 'Learning Disability Statement' (n23) paras 1.4, 2.1, 2.4 and 2.5, among others.

⁹⁴ WAG, 'Fulfilled Lives' (n15) Foreword and paras 1.4 and 1.10, among others. Independence was a core theme in the 'vision' in this document.

⁹⁵ WAG, 'Sustainable Social Services' (n7) para 2.2, emphasis added.

⁹⁶ A longer extract reads: 'We rarely expect, however, to make our big decisions on our own. We value the support that a family, however we choose to define it, provides us with. We look not for independence and separateness, but for interdependency with those around us. We also look outside our family to our web of wider friends and community for assistance'.

⁹⁷ There was one reference to 'independent living', in the sense of young people moving towards adulthood (see Section 2.1, above) in paragraph 3.36, one reference to independence as a core aim of support in relation to older people (citing principles articulated by the Chief Inspector of Social Services in Wales) in paragraph 3.37, and one reference in paragraph 3.50 to 'people at risk of losing independence', which may have been an indirect reference to the eligibility criteria set out in *CUFSAMC*.

⁹⁸ WG, 'Consultation Document' (n8). Other discussion of independence in this document was generally confined to extracts in which the obligations under *CUFSAMC* were discussed.

Where ‘independence’ could be unequivocally considered to mean either self-determination or self-reliance, there were nearly twice as many references to the latter as to the former.⁹⁹ Various references to independence in the form of self-reliance described it as a form of ‘natural’ state that should be maintained, restored or regained:

Self-care can maintain people’s independence and help them to lead lives that are as fulfilling as possible.¹⁰⁰

All but one of the references to independence in the form of self-determination occurred in relation to direct payments.¹⁰¹

The majority of the references were either ambiguous in their meaning, or were considered to refer to both ideas.¹⁰² In these documents, therefore, the meaning of ‘independence’ shifted freely between various ideas including self-reliance and self-determination. Overall, however, independence was rarely explicitly viewed as self-determination, and where it occurred in this format, it was almost entirely confined to discussion of direct payments.

6. Discussion

The overwhelming sense from these findings was that prior to the advent of the *Framework for Action on Independent Living*, the Welsh Government was essentially unaware of the narrative of independent living, its content, or its importance to the disabled people’s movement, despite the fact that it had been explicitly incorporated

⁹⁹ In the documents as a whole, there were 10 references that unequivocally referred to independence in the form of self-determination and 17 that unequivocally referred to self-reliance.

¹⁰⁰ WAG, ‘Fulfilled Lives’ (n15) para 3.13.

¹⁰¹ Nine of the ten references were directly connected to direct payments or occurred in sections discussing the use of direct payments. Five of these were in the 2004 *Direct Payments Guidance*.

¹⁰² This number was inflated by the references in CUFSAMC which, because of the definition of independence in that document, were placed in the code for ‘both’ self-determination and self-reliance. Of 51 references coded to both ideas, 44 were in CUFSAMC, leaving seven in the remaining documents. Eighteen references were coded as ‘ambiguous’. In total therefore, and excluding references in CUFSAMC, there were 25 references that were ambiguous or related to both ideas.

into Westminster disability policy from 2005.¹⁰³ Indeed, when pushed on the meaning of ‘the spirit of independent living’, the inclination of the WG had been to move away from a narrative that it either did not understand or did not wish to explore. There was, therefore, no decisive or ‘instinctive’ pull towards independent living comparable to that seen at Westminster during the same period.

The content of the *Learning Disability Statement* certainly indicated that the Welsh Government wished – in relation to people with learning disabilities at least – to shift away from ‘traditional’ or master narratives relating to disabled people and, arguably, to re-construct their identities and agency. It was also clear that it wished to devise a new narrative for social care that enabled more self-determination for those using social care support. However, as the two earliest texts demonstrated, in the case of the Welsh Government, the origin of certain of the fragments of independent living – and particularly the ideas of choice and control – was policy inherited from Westminster. The incorporation of legal guidance almost ‘wholesale’ from the Department of Health at a time when the Welsh Government was still finding its feet had embedded principles of personal self-determination, including that of individual choice, into its policy and structures. Once embedded, removing these colliding principles – which were of known and stated value to a vocal grassroots movement with which the Welsh Government was explicitly working on equality matters¹⁰⁴ – was problematic. However, as the Welsh Government developed confidence in its own identity and sought to reject principles that collided with its own discourse – replacing choice with voice – it encroached on elements of independent living that the disabled people’s movement had identified as fundamental.

It was clear, however, that the Welsh Government struggled to separate the principles of ‘choice’ and ‘voice’ and to establish a construction of ‘voice’ that was clearly distinct from ‘choice’. The texts also remained silent on how control might be enabled, without choice inevitably ensuing. While the fragments of choice and

¹⁰³ Prime Minister’s Strategy Unit and others, ‘Improving the Life Chances of Disabled People’ (TSO 2005); Office for Disability Issues, ‘Independent Living: A Cross-Government Strategy about Independent Living for Disabled People’ (HM Government, 2008). Of these documents, ‘Life Chances’ was applicable in Wales in relation to non-devolved matters while the ‘Independent Living Strategy’ pertained only to England.

¹⁰⁴ See Chapter 3, section 3.

control are interconnected, to an extent, the principles of control and *voice* are mutually exclusive – while control suggests power, management and ownership, *voice* suggests – as a maximum – involvement and, if acted upon, influence. While the colliding fragments of choice and control were present, they therefore remained somewhat incoherent in their content and meaning. The conscious or unconscious response of the Welsh Government to these difficulties and latent conflict was essentially to obscure the meaning of these fragments, and to ‘bundle’ them together with the mechanism of direct payments. In these texts, direct payments – also inherited from Westminster – effectively became the repository of various troublesome elements of independent living – particularly choice and control and the construction of independence in the form of self-determination. Direct payments allowed the Welsh Government to give access to these inherited and colliding principles while ‘containing’ or restricting them to a particular form of support delivery that was also inherited. How these principles would sit with other aspects of social services was largely unexplored.

In these early documents, there appeared to be no clear attempt to capitalise on areas of adjacency between the counter-narrative and Welsh Government policy principles. In discussion of communities and inclusion, any connection between these narratives seemed coincidental rather than an intentional attempt to demonstrate connections – a fact that was emphasised by the almost complete lack of substantive references to equality, and the very limited discourse of rights. Of interest, however, was the reference in *Fulfilled Lives* to the social model, which indicated that the Welsh Government was aware of the ideas of the disabled people’s movement and not averse to incorporating them. It is of note that – as indicated in Chapter 8, section 2.1 – the social model speaks to the *collectivist* principles articulated by the disabled people’s movement rather than the more individualistic ideas present in independent living.

These documents demonstrated the introduction of scattered fragments of independent living, rather than an interest in a solid counter-narrative that consistently radicalised the identity and agency of disabled people or social care principles. There were, however, hints that possibilities might exist in Wales for independent living to emerge in a form that built upon the principles of mutuality and

collectivism that were of value to both the Welsh Government and the disabled people's movement. The rejection of the notion of independence in *Sustainable Social Services* and the *Consultation Document*, and the desire to develop social care structures that furthered the principles of mutuality, echoed the ideas of the 'dissenters' in the movement, who sought *integrated* living, and forms of support that were not based on individualism. Various hurdles existed. It was, first and foremost, necessary for the Welsh Government to grasp the idea of independent living and commit to it. It would then be necessary to find a 'bridge' between the colliding ideas, and seek to develop a form of independent living that was capable of functioning within the Welsh Government communitarian narrative while still remaining true to the essential principles devised by the disabled people's movement, both in Wales and the UK more broadly.

7. Conclusion

This introductory chapter has demonstrated that prior to any stated attempt by the Welsh Government to incorporate independent living into policy, fragments of the narrative were present, albeit introduced through inherited policy and existing in a somewhat confused form. While there was a stated interest in reconceptualising the identity of disabled people, the lack of coherence in the incorporated fragments did not, at this stage, enable such a reconceptualisation to take place in any consistent way, and the problems posed by colliding ideas were obscured rather than tackled. If the Welsh Government were to transpose independent living directly into policy, it would need to explore both colliding and adjacent themes in more depth, and deal with any difficulties posed by both. The following chapter demonstrates how the fragments of independent living were constructed in the 2013 *Framework* and the implications of this for the effective functioning of the counter-narrative.

Chapter 10: The Framework for Action on Independent Living

1. Introduction

This chapter focuses on the *Framework for Action on Independent Living* ('the *Framework*')¹ – a document that was created to bring the independent living counter-narrative into Welsh Government policy. It considers whether the construction of independent living in the *Framework* supports the repaired identity and agency of disabled people crafted by the counter-narrative and whether the master narratives identified by the disabled people's movement are effectively refuted. In particular it considers how the Welsh Government has handled aspects of independent living that collide with or are adjacent to the Welsh Government communitarian narrative, and how far it has accepted the principles of independent living where the matter of state-funded social care is concerned.

The Welsh Government published the *Framework* on 19 September 2013.² Its history is given in Chapter 3, section 6.2. In summary, it was created by the Welsh Government in response to a combination of the campaign for independent living coordinated by Disability Wales in 2010 and the roughly contemporaneous investigation by the Joint Committee on Human Rights into the implementation of the right of disabled people to independent living at which representatives from both

¹ Welsh Government, 'Framework for Action on Independent Living' (2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018.

² The *Framework* is available electronically in PDF and Word formats. The page numbers given in footnotes are to the PDF version. At the time of writing the *Framework* and accompanying documents were no longer easily available on the Welsh Government website but could be accessed via the search facility at <<http://gov.wales/topics/people-and-communities/equality-diversity/rightsequality/disability/framework-for-action/?lang=en>> accessed 31 July 2019.

Disability Wales and the Welsh Government gave evidence.³ The *Framework* is stated to be the means by which the Welsh Government will implement the UNCRPD in Wales, including Article 19.⁴

At the time of writing the *Framework* was undergoing revision. The revised policy, *Action on Disability: The Right to Independent Living* was published by the Welsh Government for consultation on 22 October 2018.⁵ Owing to its publication date, it was not possible in the timescale of the project to incorporate this document into the study, but some thoughts on it are given in the final chapter of this thesis.

2. An overview of the *Framework* and the definition of ‘independent living’

The *Framework* provided a compelling case study for the examination of the impact on an activist counter-narrative of its incorporation into policy. It was developed by the Welsh Government in close consultation and cooperation with disabled people’s organisations and other third sector groups.⁶ The process was guided by a steering group which included Disability Wales and All Wales People First,⁷ as well as non-user-led disability charities and organisations representing other interests including local government and the NHS.⁸ The *Framework* is promoted by both Welsh

³ Specifically, the Framework was a response to the submission of the Disability Wales Manifesto for Independent Living to the Petitions Committee of the National Assembly for Wales in 2011. Welsh Government, ‘Equality Impact Assessment on the Framework for Action on Independent Living’ (June 2012, revised and updated July 2013) <<http://gov.wales/docs/equality-impact-assessments/141106-EIA-Framework-for-Action-on-Independent-Living-2013-Review.pdf>> accessed 31 July 2019.

⁴ Page 4.

⁵ Welsh Government, ‘Action on Disability: The Right to Independent Living’ (2018) <<https://beta.gov.wales/action-disability-right-independent-living>> accessed 26 October 2018.

⁶ Disability Wales was particularly involved in this process. Disability Wales, the Welsh Government and others state that, after its initial phase, the Independent Living NOW! campaign run by Disability Wales supported the Welsh Government in developing the Framework. Disability Wales and others, ‘The Enabling Wales Toolkit’ (undated but believed to be March 2017) <<http://www.disabilitywales.org/wp-content/uploads/2018/03/Enabling-Wales-Toolkit-March-2017.pdf>> accessed 31 July 2019. The Disability Wales ‘Manifesto for Independent Living’ was said to be the starting point for the first draft of the Framework. Welsh Government, ‘Minutes of the Disability Equality Advisory Group, 2 November 2011’, para 4.2. No longer readily available online.

⁷ People First is a national network of self-advocacy groups of people with learning disabilities. The website of All Wales People First is at: <<http://allwalespeople1st.co.uk/>> accessed 22 February 2019.

⁸ The steering group included representatives from large disability-related charities including, for example, Leonard Cheshire Disability and National Autistic Society Cymru; and organisations

Government and Disability Wales as a co-produced document⁹ and repeated Governmental reference has been made to the fact that the *Framework* was developed around priorities identified by disabled people.¹⁰ The *Framework* therefore offered a unique opportunity for the disabled people's movement in Wales to insert the principles and content of independent living into government policy, although other stakeholders with potentially conflicting interests were also involved.

The *Framework* drew heavily on the 2011 Disability Wales *Manifesto for Independent Living*.¹¹ A section that explained independent living reproduced and gave a specific commitment to the short 'definition' of independent living provided in the *Manifesto*¹² and one chapter was based around the priorities identified in the *Manifesto*. 'Choice and control' was listed as one of four core values upon which independent living depends (the others were 'confidence', 'co-operation' and 'co-production'¹³) and a further chapter listed nine intended 'outcomes' of independent living that reflected, to a large extent, the 12 pillars of independent living identified by the disabled people's movement.¹⁴ The social model of disability was placed at the core of the *Framework*, referenced both by name and by frequent allusions to 'barrier removal', and overall, barrier removal and access formed the main focus of the document. The *Framework* also cited Article 19 of the UNCRPD. The document therefore contained a number of direct and indirect claims that an aim of the document was to bring independent living, as devised by the disabled people's movement, and as articulated in the UNCRPD, into Welsh Government policy.

representing other interests including Wales Council for Voluntary Action, the Chartered Institute of Housing, Welsh Local Government Association and the NHS Centre for Equality and Human Rights.

⁹ Disability Wales and Welsh Government, 'Independent Living in Wales: Update Bulletin' (September 2014) <<http://gov.wales/docs/dsjlg/publications/equality/140929-framework-bulletin-en.pdf>> accessed 31 July 2019. The Framework consultation was launched at the offices of Dewis Centre for Independent Living. Dewis CIL, 'Framework for Action on Independent Living Launch' (21 September 2012) <<https://www.dewiscil.org.uk/framework-for-action-on-independent-living-launch>> accessed 11 April 2018..

¹⁰ WG 'Framework' (n1); WG, 'Equality Impact Assessment' (n3).

¹¹ Disability Wales / Anabledd Cymru, 'Manifesto for Independent Living' (2011)

<http://www.disabilitywales.org/wordpress/wp-content/uploads/Manifesto_for_IL_E.pdf> accessed 11 November 2016.

¹² Discussed in Chapter 7, section 3.

¹³ These are discussed below.

¹⁴ See Chapter 2, section 4.

The *stated* aims of the *Framework*, however, made no reference to independent living, although they referred to the need to challenge dominant discourses. These aims were largely connected with Welsh Government priorities, including resource constraints, expressed as an imposition from the Westminster government. The stated aims were:

- to set out a positive vision for disabled people in Wales in the challenging context of recession and the UK Government's programme of welfare reform, combined with public expenditure cuts;
- to challenge stereotypes and negative attitudes;
- to bring together for the first time a strategic approach to disability in Wales bringing together issues that have previously been dealt with separately;
- to set out what the Welsh Government is doing across portfolios to promote an inclusive and enabling society;
- to highlight the key roles of local delivery partners and stakeholders.¹⁵

In addition, and as noted above, the *Framework* placed particular importance on the social model of disability:

The primary focus of the *Framework* is on the social model of disability...¹⁶

The definition of independent living provided in the *Framework* also starts with the statement that the *Framework* 'gives practical effect to the social model of disability which the National Assembly for Wales adopted in 2002.'¹⁷

Welsh Government principles were echoed throughout the document. For example, the Foreword stated (emphases added):

¹⁵ Page 7. In addition, in relation to challenging narratives, there is also a statement in the Framework that 'The social model requires culture change and leadership across government, public services and the private sector in Wales'. Page 8.

¹⁶ Page 8.

¹⁷ Page 7. See further below.

Where support is needed, it should promote independent living and ensure *voice and control* in how services are provided. That is a guiding principle of our programme of reform of social services in Wales as we recognise that this will contribute to creating an inclusive and enabling society, and promote *well-being* for all.¹⁸

Other statements in the *Framework* indicated its importance in fulfilling the Welsh Government's obligations under legislation including the UNCRPD and the Equality Act 2010. As noted in Chapter 3, section 6.2, the Welsh Government has always stated that the *Framework* supports its Strategic Equality Plan and Objectives (SEP). The SEP current at the time of writing places independent living in its first objective, which reads:

.....Specifically ensure support and tackle barriers to enable disabled people to enjoy their right to independent living and have voice, choice and control in their lives'.¹⁹

Social care was to some extent sidelined in the *Framework*. This was largely for reasons of timing. At the time of the consultation on the *Framework*, the passage of the Social Services (Wales) Bill through the National Assembly was already underway.²⁰ Information around the *Framework* indicates that the Welsh Government considered this forthcoming legislation would be the means of connecting social care arrangements to the outcome of independent living.²¹ Two

¹⁸ Page 4.

¹⁹ Welsh Government, 'Strategic Equality Plan and Equality Objectives: 2016-2020' (2016) <<https://gov.wales/sites/default/files/publications/2019-03/equality-plan-and-objectives-2016-2020.pdf>> accessed 8 July 2019, 6. This is altered and re-prioritised from the first Welsh Government SEP, in which Objective 5 stated: 'Tackle barriers and support disabled people so that they can live independently and exercise choice and control in their daily lives'. Welsh Government, 'Strategic Equality Plan: 2012-2016' (2012) <<https://gweddill.gov.wales/docs/dsjlg/publications/equality/120405sepfinal-en.pdf>> accessed 8 July 2019, 11.

²⁰ The consultation on the Social Services (Wales) Bill was launched on 12 March 2012 and the consultation on the Framework in September 2012.

²¹ During the consultation process on the Framework, a number of working groups were set up to investigate and consider five of the seven prioritised issues. No group was established to consider support provided through social care as this was deemed to be covered through the legal reform, which was subject to its own consultation process. See, Welsh Government, 'Equality Impact Assessment' (n3). The connection between the forthcoming legislation and the Framework was also noted in the minutes to the Welsh Government cabinet meeting on 10 July 2012, which state: 'The

sections of the *Framework* were devoted to social care (3.4 and 4.3). These sections were comparatively brief²² and made heavy reference to the forthcoming legislation.²³ The legislation itself is examined in the following chapter of this thesis.

This partial marginalisation of social care in the *Framework* had the effect of creating a distinction between those who did not need social care and those who did, with certain needs of the latter group separated out and transferred to legal processes. This separation was not necessarily *intentional* but was unmistakable. In addition to references that emphasised how few disabled people require social care support,²⁴ the *Framework* stated:

While we acknowledge that some disabled people are reliant on specific support, many others just want to be able to participate in life in the same way as everyone else. Where support is needed, it should promote independent living and ensure voice and control in how services are provided.²⁵

This statement explicitly created a difference between those who need support in daily life and those who do not. It suggested that that disabled people who need support had different aspirations from others and lacked social and life ambitions. While it challenged narratives of difference for the majority of disabled people by

actions the Welsh Government was taking to deliver the Sustainable Social Services White Paper and the Social Services (Wales) Bill would support the aspirations in the Independent Living Framework'. Welsh Government, 'Cabinet Meeting 10 July 2012: Minutes' (2012) <<https://webarchive.nationalarchives.gov.uk/20180413015524/http://gov.wales/about/cabinet/meetings/previous-administration/10jul12/?lang=en>> accessed 8 July 2019, item 5, para 5.5. The passage of the Social Services and Well-being (Wales) Act 2014 was also noted in updates on the Framework jointly published by the Welsh Government and Disability Wales. Welsh Government and Disability Wales (n9).

²² In terms of length the sections on various outcomes in Chapter 3 ranged from half a page (access to CILs) to three pages (employment). The section on social care was just over a page long. The sections in Chapter 4 on social care was the shortest at just over two pages. The section on information and advice was slightly longer, and the sections on housing, person-centred technology, transport, access and employment ranged from four to five pages long. None of the case studies discussed social care support.

²³ Both sections contained much information as to the provisions of the forthcoming Social Services and Well-being Bill. Section 4.3 contained the statement that, '[t]his Framework has been informed by the consultation and engagement with disabled people that took place during the development of the [programme for the reform of social services provision in Wales]' (page 45).

²⁴ 'The majority of disabled people are not in receipt of social services' (page 10, in a section entitled 'Scope of the Framework'). Various figures on this theme are given at the bottom of page 45, including a statement that in the year 2011-2012, '[a]round 1.5% of the population aged 18-64 years received social service care'.

²⁵ Page 7.

aligning them with 'everyone else', it simultaneously created a narrative of otherness and dependency for those with the most severe impairments – that is, the group that originally created independent living. The impact of this separation is discussed below.

The *Framework* contained a definition of independent living which set out the Welsh Government's understanding of the concept. This passage reads:

The Framework for Action gives practical effect to the social model of disability which the National Assembly for Wales adopted in 2002. This recognises that people are disabled by the barriers created by society, and that the guiding principles of policy should be:

- to remove these barriers and create an enabling society
- to promote the rights and full inclusion of disabled people.

Independent Living expresses the rights of disabled people to participate fully in all aspects of life. The Welsh Government supports the following definition of independent living:

'Independent Living enables us as disabled people to achieve our own goals and live our own lives in the way that we choose for ourselves.'²⁶

In this document the term 'independent living' is used in two ways:

- to express the aspirations of disabled people as set out above
- to describe an approach to public service provision that supports and empowers this aspiration.²⁷

²⁶ Page 7. This is the expression of independent living found in the Disability Wales 'Manifesto for Independent Living' (n11). A footnote in the *Framework* describes this statement as a "Definition adopted by Disability Wales and partner organisations during consultation on a Manifesto for Independent Living, 2011." (Footnote 1, page 7).

²⁷ Page 7.

The definition is immediately followed in the *Framework* by a section on the UNCRPD, in which Article 19 is paraphrased in the following terms:

- disabled people have an equal right to live in and take part in the community;
- disabled people have the right to the same choice and control as non-disabled people; and
- Governments should do everything they can to ensure disabled people enjoy these rights.²⁸

This passage holds various indications that the Welsh Government had not fully understood independent living. In terms of the counter-narrative of the disabled people's movement, it was incomplete. While it contained the notions of the social model, rights, choice, inclusion, participation, and a meaningful life, and conveyed a sense of empowerment, other essential elements were missing. These included equality, control, the existence of 'ordinary' social roles in 'mainstream' life, the rejection of institutional living, and the crucial distinction between self-determination and self-reliance. In addition, the paraphrasing of Article 19 fell significantly short of the Article itself, lacking specificity both as to the precise content of the rights conferred by the Article and the nature of the obligations on the state to meet these.²⁹ Equally important, perhaps, there were no allusions in the *Framework* to the fact that independent living and the social model of disability were developed by, and creatures of, the disabled people's movement.³⁰ The absence of this point obscured the radical nature of independent living and its importance as part of a collectively repaired identity; and lessened the 'ownership' of independent living by the movement.

3. The fragments of independent living

²⁸ Page 7. This statement of Article 19 was also contained in supporting documents, such as the Welsh Government, 'Equality Impact Assessment' (n3)

²⁹ The full text of Article 19 is given in Chapter 3, section 4 and is discussed in Chapter 6, section 5.

³⁰ It is noted in Chapter 7 section 2 that a statement to this effect was also missing from the Disability Wales 'Manifesto for Independent Living' (n11).

All the fragments of independent living identified in Chapter 6 of this thesis appeared in the *Framework*.³¹ Numerically, there was a different level of emphasis from the texts in the disabled people's movement datasets. A table providing the numbers of references to the various fragments is provided in Appendix 8. In particular, there was a very heavy focus on inclusion, and a strong focus on equality – both identified in the Chapter 8 as 'adjacent' themes.³² Both inclusion and equality were mentioned more frequently than either choice or control, which were definitional in the texts from the disabled people's movement in the Anglo-British and Welsh texts. Choice was referenced more frequently than control, although this was reversed where social care was under discussion.³³ Indeed, in numerical terms, control was referenced less frequently than participation, employment, and rights, and a similar number of times as the Welsh Government's own principle of 'wellbeing'.³⁴ Wellbeing itself was threaded through the document, typically appearing as a generalised idea.³⁵ Wellbeing was related to social care, where it was applied both to disabled people³⁶ and to society more widely.³⁷ It was particularly aligned with health,³⁸ and was also applied to the environment.³⁹ It was connected both to fragments of independent

³¹ As stated in Chapter 5, given the nature of the *Framework*, the entire content was searched for discussion of all the fragments identified in Chapter 6 and all relevant extracts were coded, rather than solely extracts in which the phrase 'independent living' appeared.

³² In the document as a whole, there were 72 references to inclusion (with a further 11 references to inclusive design) and 34 references to equality, excluding 18 references to strategies, documents, plans and legislation relating to equality. There were a further 20 references to 'everyone' or 'all' or similar, six of which had a strong sense of equality.

³³ In the document as a whole there were 38 references to choice and 18 to control.

³⁴ There were 38 references to participation, 29 to rights, 28 to employment and 17 references to wellbeing. There were 18 to control.

³⁵ 'The Bill includes provision to...introduce a collective responsibility for local authorities and LHBs towards their citizens' well-being to ensure there is quality accessible information about a range of services in the community.' Page 18.

³⁶ 'The design of these services, how needs are assessed, and the quality and efficiency of provision, are all crucial to people's well-being and quality of life.' Page 44.

³⁷ 'That is a guiding principle of our programme of reform of social services in Wales as we recognise that this will contribute to creating an inclusive and enabling society, and promote well-being for all.' Page 4.

³⁸ Wellbeing was connected with – or placed adjacently to – health in seven out of the 17 extracts in which it appeared.

³⁹ 'The aim is to ensure that in pursuit of a better long-term future, the best possible decisions are made that achieve the maximum possible long term benefits to the economic, social and environmental wellbeing of Wales.' Page 12.

living such as inclusion, participation⁴⁰ and employment,⁴¹ and to independent living itself – where it was also associated with the idea of a lack of reliance on public services.

‘Public authorities should be encouraged to take a long-term view and recognise the benefits of independent living in terms of well-being for individuals, which can lead to less reliance on public services.’⁴²

3.1 Personal agency

In the texts from the disabled people’s movement, the narrative of personal agency was developed as a direct challenge to master narratives of deficit, passivity, vulnerability and sub-humanity, acting as a powerful form of resistance to the deprivation of opportunity and the infiltrated self. Personal agency was comprised of fragments of independent living relating to self-determination, demonstrating that individuals had their own values, ideas and ambitions. A ‘mantra’ of choice and control was swiftly developed and there were demands that control should be transferred from professionals to the individual. Personal agency extended beyond the notion of moral agency considered by Nelson and was expressed as an inherent part of the human condition for all people, including those with restricted mental capacity. Similar characteristics were found in the Welsh DPM texts, although these demonstrated a stronger focus on choice than control.

In Chapter 8 the individualism inherent in personal agency, and particularly the idea of choice, is identified as a concept that collides with the Welsh Government communitarian narrative. In the Welsh Government policy documents prior to the *Framework* the idea of control was, however, reasonably prominent. Choice carried less weight and in the latter texts, in which the Welsh Government was increasingly

⁴⁰ An additional issue is how to achieve effective engagement of Access Groups with public services and private developers, to ensure that all buildings and public spaces are accessible, safe and welcoming for all, and thus promote inclusion, participation and well-being.’ Page 62

⁴¹ ‘Stakeholders emphasised the crucial role of employment in promoting people’s independence, confidence, health and well-being, providing a route out of poverty and enabling participation in society.’ Page 64.

⁴² Page 9. See further comment on this extract in section 4.1 below.

asserting its own personality, gave way to ‘voice’, which is less powerful in terms of personal agency. Self-determination was certainly a concept that was very present in the *Framework*. In one extract self-determination was cited as a new narrative that stood in direct contrast to former narratives of passivity and helplessness, although this idea had come originally from a source *external* to the Welsh Government.

[Person-centred technology] can support the paradigm shift from “disabled people being objects of care” to “disabled people being able to self determine their life and increase their independence”.⁴³

The fragments of choice and control, which were expressed as definitional to independent living in the texts from the disabled people’s movement, were also centrally placed in the *Framework*. As noted in section 2 above, choice and control appeared as one of the four core values upon which independent living was stated to depend. The expression of this value contained a strong sense of equality – no distinction was made between disabled and non-disabled people, and both groups were identified as needing support:

Choice and control – individuals having the same choice and control as other people in the way they live their lives and receive support from others.⁴⁴

Choice and control were expressed as being applicable to the whole of one’s life:

Where buildings are well and inclusively designed, most disabled people are able to maintain an independent lifestyle, in their own home, enjoying the same choices and control over their lives as everyone else...⁴⁵

⁴³ Page 48. The concept of a shift in narrative here originated from the ‘ImPaCT in Europe’ project conducted by the European Commission, in which Learning Disability Wales took part. It reflects the idea of a ‘paradigm shift’ in narrative that surrounded the development and content of the UNCRPD (see Chapter 2, section 4 and Chapter 6, section 5.

⁴⁴ Page 14.

⁴⁵ Page 41.

Both choice and control were also expressed as relating to one's support. One of the nine intended outcomes of independent living listed in Chapter 3 of the *Framework* was:

[Disabled children and adults] having more control over their lives by being able to make choices in the care and support they receive.⁴⁶

As this extract indicates, in the context of social care, choice and control were generally restricted. In the *Framework* as a whole both choice and control were typically unqualified. However, where social care was under discussion this was reversed, with the ideas of having *more* or *greater* choice and control more commonly expressed.⁴⁷ In these sections, the Welsh Government's principle of 'voice' also on occasion supplanted that of choice.⁴⁸ Voice was also qualified:

The voice and control of service-users, including children and young people, will be *maximised as far as possible* in the assessment and planning of care and support arrangements... (emphasis added).⁴⁹

In addition, the concept of 'voice' was not applied to the lives of people who did not need support. The *Framework* therefore contained a clear distinction of both identity and agency between those requiring support in daily life and those who did not, despite the *stated* core value that disabled people would experience 'the same choice and control as other people'. As is discussed in Chapter 6, section 4.1, *more* control is not necessarily equal to control; and having *choices* may not be the same as full or equal choice.⁵⁰

⁴⁶ Page 17 and pages 20-21.

⁴⁷ In the document as a whole, there were seven references to having choice over one's support, of which five were qualified; and six references to having control over one's support, of which four were qualified. Of the unqualified references, two appeared in relation to direct payments and one in discussion of the work of a CIL. The remaining one appeared in a statement of vision.

⁴⁸ Including all references in titles and subheadings, the phrase 'choice and control', or close variations, appeared eight times in the *Framework*, two of which were in connection with social care support and one of which related to both social care support and life beyond this. The phrase 'voice and control' or close variations appeared on three occasions, always in relation to social care support (plus one reference in the name of a project). Where social care support was under consideration, therefore, the notion of 'voice and control' was slightly more prevalent than 'choice and control'.

⁴⁹ Page 21. See also, ...and it will bring a clearer focus on meeting the needs of individuals, and enabling them to have a stronger voice in, and greater control of, the support they receive' (page 45).

⁵⁰ See the discussion in Chapter 6, section 4.1.1.

As in the texts from the Anglo-British and Welsh DPM datasets, choice and control, and particularly the former, were strongly connected to the narrative of social agency, with references to choice over leisure,⁵¹ one's home or living arrangements,⁵² education⁵³ and employment,⁵⁴ although these were often expressed as a current *denial* of choice or control. Both ideas were also connected to rights.⁵⁵ These included expressions of choice as a pre-existing right, or a quality to which individuals are entitled by nature of their humanity.

The Framework respects the rights of individuals to have freedom of choice in how they live their lives and helps supports the rights of disabled people.⁵⁶

3.2 Social agency

The texts from the disabled people's movement created the narrative of social agency as a direct subversion to master narratives of sub-humanity, deficit and inferiority that resulted in policies enabling profound social exclusion to the extent of enforced 'incarceration'. The narrative of social agency was based around a core value of non-institutional community living and contained other fragments including inclusion, participation, and having a meaningful life. Disabled people were reinvented as fully included and equal social actors expecting, holding and fulfilling a range of typical social, community and family roles. In the narrative of social agency, exclusion and segregation from society were established as unnatural states and

⁵¹ See, for example, 'Access to the natural environment enables disabled people to have the same choices for leisure and holidays as everyone else', page 58.

⁵² For example, 'In relation to supported living, people with learning disabilities report that their feelings in relation to their home situation e.g. whether they are happy to share, and who with, are sometimes not recognised.' Page 42.

⁵³ For example, 'Access barriers to schools have the effect of limiting choice of school so that, for example, disabled primary school pupils are separated from friends at secondary transition.' Page 60.

⁵⁴ For example, 'For example, many disabled people rely on public transport. If they are unable to use buses or trains, that is a major constraint on the employment options available to them. Similarly, the availability of suitable housing limits people's ability to move to find employment.' Page 14.

⁵⁵ Rights were connected more strongly to choice than to control. They were connected to choice on four occasions and to control on one. It should be noted here, of course, that there were more references to choice than to control overall.

⁵⁶ Page 8.

resisted with the construction of identities and agency for disabled people that relied on the ideas of sameness and equality. The narrative of social agency therefore both rejected the deprivation of opportunity caused by the identified master narratives and provided a tool for disabled people to resist the infiltrated self. The narrative was also seen in the Welsh DPM documents.

The communitarian content of social agency suggested that it was an aspect of independent living that was more obviously adjacent to elements of the Welsh Government communitarian narrative. Despite this, the narrative of social agency was only dimly present in the Welsh Government documents prior to the *Framework*, with the exception of the *Learning Disability Strategy*. In contrast, in the *Framework*, social agency was the most vividly and faithfully reproduced of the three central threads of independent living. The *Framework* placed importance upon all the core fragments of social agency that existed in the texts from the disabled people's movement. It is noted above that inclusion was by some way the most frequently referenced of all the fragments of independent living that were identified in Chapter 6 of this thesis. The fragments of community living, participation and a meaningful life were also incorporated to produce a similar narrative in the *Framework* of disabled people as competent social actors with various roles. This extended to individuals who required assistance in daily life:

The Independent Living Institute points out that disabled people are customers, workers, students, parents, taxpayers and voters, and community members. The purpose of any form of support should therefore be to enable people to overcome the practical barriers they face to participating in all of these roles and activities.⁵⁷

The *Framework* contained five case studies, in the words of disabled people, which contributed strongly to the narrative of social agency. In these, the speakers constructed themselves as people with lives to lead and as users of community facilities, including schools, banks, public transport, shops and libraries, although

⁵⁷ Page 10.

these roles were typically expressed in terms of the structural *denial* of such opportunities. For example:

I want to be able to fill in forms; complete the electoral register; listen to my Bank statements; order my shopping; attend appointments and check my energy bills.⁵⁸

None of these case studies discussed the use of social care; and in the sections of the *Framework* that related to social care, the narrative of social agency was highly constrained. For example, a reference to personal assistance stated:

This can be very empowering, enabling people to go out more rather than stay at home to receive traditional forms of care, and giving them direct control over how they spend their day and how and when services are provided.⁵⁹

This extract was a vivid contrast with the discussion of social roles, including employment and family responsibilities, that was present elsewhere in the *Framework* and in the texts from the disabled people's movement. Despite the references to empowerment, 'go[ing] out more' and how people 'spend their day', there was little similarity to the vision of free, full, unhindered and meaningful lives envisaged elsewhere in the document.

Inclusion had a particular place in the *Framework*, placed centrally and appearing very frequently. The adjacency of inclusion to the Welsh Government's communitarian narrative is noted in Chapter 8. This adjacency was reflected in the frequency of the references to inclusion in the *Framework*. Inclusion was often expressed as a relatively generalised aspiration, alongside – but not necessarily connected to – independent living. Such references frequently referred to an 'inclusive and enabling society'. Indeed, as noted above, one of the stated aims of the *Framework* was:

⁵⁸ Page 38.

⁵⁹ Page 46.

... to set out what the Welsh Government is doing across portfolios to promote an inclusive and enabling society...⁶⁰

This phrase, or variants of it, occurred on twelve occasions in the *Framework*.⁶¹ It indicated a broad general principle and overarching vision that Disability Wales had been instrumental in formulating.⁶² However, the *Framework* also contained a statement that implied that inclusion and participation were not necessarily available to all disabled people:

...there are **many** disabled people who would be able to participate fully in society if the barriers to inclusion were removed (emphasis added).⁶³

The *Framework* contained a strong focus on employment, which was listed as an enabler of independent living.⁶⁴ Employment was seen not simply as an aim in itself, but as the means to other ends.

Stakeholders emphasised the crucial role of employment in promoting people's independence, confidence, health and well-being, providing a route out of poverty and enabling participation in society.⁶⁵

That some disabled people would not be able to work was discussed in positive terms, directly referencing the need to shift existing narratives.

⁶⁰ Page 7.

⁶¹ These twelve instances included two in which the ideas of inclusion and enabling occurred closely together.

⁶² Disability Wales stated it was 'instrumental in formulating the overarching strategic vision of "An enabling society in which disabled children and adults enjoy the right to independent living and social inclusion". Disability Wales, 'It's Time to Create an Enabling Wales' (*Disability Wales*, 5 December 2013) <<http://www.disabilitywales.org/its-time-to-create-an-enabling-wales/>> accessed 25 February 2019.

⁶³ Page 8.

⁶⁴ There were 29 references to employment in the Framework, including one 'block coded' section (see Appendix 5).

⁶⁵ Page 64.

In trying to do everything possible to support disabled people's aspirations to work, we should not reinforce the stigma on people who are unable to do paid work, but value the contribution they are able to make.⁶⁶

The focus on employment reinforced the narrative of disabled people as actors carrying out typical and socially valued roles. However, employment was particularly considered in the context of CILs and other DPOs,⁶⁷ voluntary work, sheltered employment and supported businesses.⁶⁸ Only one of the case studies discussed employment in detail, in which it appeared in the form of unpaid work, work experience and work 'placements'.⁶⁹

There were numerous indications throughout the *Framework* that disabled people living and participating in the community was the accepted underpinning principle and a 'default' position.⁷⁰ This was another area of adjacency between independent living and the Welsh Government communitarian narrative. As the extracts cited above demonstrate, disabled people were consistently portrayed as being and acting within community settings. Housing, and the need for accessible housing stock, was a strong focus, although the dependence of disabled people on social housing and rented accommodation was not significantly challenged. It was acknowledged that people with learning disabilities often lacked control over tenancies and choice of co-tenants,⁷¹ with one passage recalling the sense of compulsion that had been expressed in this context in the texts from the disabled people's movement:

⁶⁶ Page 65.

⁶⁷ One such reference indicated that these organisations were anticipated as providing a source of unpaid expertise. 'Local Authorities, Local Health Boards and other local service providers can help deliver the outcomes of this Framework by, for example:... considering how they can support and work with disabled people's organisations in their area. A relatively small amount of resource can unlock a huge amount of voluntary time and expertise, but many groups find it impossible to get this support...'. Page 33.

⁶⁸ While employment was positioned as one of the 12 pillars of independent living in the Anglo-British DPM dataset, in those documents, employment was typically discussed in terms of 'mainstream' jobs rather than jobs that related specifically to disability (such as work in a CIL). Sheltered employment and supported businesses were not connected to the idea of independent living in these texts.

⁶⁹ 'Beth's story' on page 67. In addition, there was passing reference to letters relating to employment in 'Julie's story (1)' on page 38 and discussion in 'Tony's story' of the foundation of a campaigning group and a campaigning network of organisations, which implied either voluntary or paid commitment.

⁷⁰ This was particularly expressed in the case studies.

⁷¹ 'In relation to supported living, people with learning disabilities report that their feelings in relation to their home situation e.g. whether they are happy to share, and who with, are sometimes not recognised. More fundamentally, their rights as tenants of their own home are sometimes not

Article 19 of the UNCRPD says that Governments should ensure that disabled people have the right to choose where they live and who they live with – no disabled person should be *unlawfully forced* into a particular living arrangement (emphasis added).⁷²

The meaning of this sentence is unclear. If suggesting that forcing an individual into a particular living arrangement is always unlawful, it is a solid statement of the principles of Article 19 of the UNCRPD. If, in contrast, it is intended to suggest that forcing an individual into a particular living arrangement is acceptable, so long as it is legal under domestic legislation, it goes against the right enshrined in Article 19 and the spirit of independent living. In England and Wales disabled people have been, and continue to be, forced into ‘particular living arrangements’ in a variety of ways, such as a failure or refusal to fund or provide alternatives,⁷³ or through the provisions of the Mental Capacity Act 2005 and the Mental Health Act 1989.⁷⁴ Despite lack of clarity in this statement, and the potential under domestic legislation for disabled people to be required to live in particular settings regardless of their choices, there was no coherent discussion of the place, or the lack of it, of residential or institutional support in independent living, and no explicit rejection of enforcement that might be lawfully achievable.⁷⁵

recognised. Plans are made to change their co-tenants, or the staff who provide their personal support, with little or no consultation with the people affected.’ Page 42.

⁷² Page 41.

⁷³ See, for example, the comment noted in research by Morris and cited in Chapter 6 of this thesis: ‘I chose to go into residential care - it is just that it was the only choice there was’. For a case that considers this matter in the English context, see *R (on the application of D) v Worcestershire CC* [2013] EWHC 2490 (Admin).

⁷⁴ The Mental Capacity Act 2005 requires decisions to be made about a person in their ‘best interests’ if the law states that they do not have the capacity to make a decision themselves. In certain circumstances, individuals can also be detained and hospitalised, or required to live in a particular arrangement under the Mental Health Act 1989.

⁷⁵ There is evidence that resource constraints are forcing disabled people back into residential accommodation as adequate support is not available in the community, or because a care home placement is deemed to be cheaper. This is particularly true of people who receive support via the NHS as ‘continuing health care’ rather than through local authorities. See, May Bulman, ‘NHS Cost Cutting Leaving Disabled People “Interned” in Care Homes’ *The Independent* (London, 25 October 2017); Frances Ryan, “‘I Could Be Taken From My Home’: Why Disabled People Once Again Fear Being “Warehoused”’ *The Guardian* (London 27 March 2018). The UN Committee on the Rights of Persons with Disabilities raised concerns about this in their report following its 2017 investigation into the UK. See UNCRPD Committee, ‘Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland’ (3 October 2017)

<https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fGBR%2fCO%2f1&Lang=en> accessed 31 July 2019. That this is a real fear for individuals in Wales

3.3 Equality and rights

In the texts from the disabled people's movement, the fragments of equality and rights, and particularly the latter, performed a distinctive function. In constructing disabled people as equal and entitled citizens, these fragments repudiated master narratives of difference, worthlessness and sub-humanity and also positioned independent living as a matter of social justice and legal identity. In addition, the theme of rights politicised the discussion and acted both as a form of narrative repair for the damaged identity and as a campaigning strategy for disabled people. In certain texts, rights were crafted as a third counter-narrative for the disabled people's movement, alongside independent living and the social model, although it was acknowledged that this created difficulties in treading the ground that was occupied by dominant discourses of deficiency. In the Welsh DPM documents both rights and equality were strongly present, although equality appeared rarely in the extracts directly relating to independent living.

Both equality and rights were 'adjacent' concepts, appearing in both the independent living counter-narrative and the Welsh Government communitarian narrative. However, equality was largely absent in the texts prior to the *Framework*, and rights generally related to specific legal entitlements. Despite this adjacency, approaches to equality and rights were ambivalent in the *Framework*. Many references were made to both fragments, but the themes often lacked the force and purpose that was expressed in the texts from the disabled people's movement.

is illustrated by the case of Nathan Lee Davies, who has campaigned against the closure of the Welsh Independent Living Grant. See, James Williams, 'Independent Living Grants: Disability Campaigner Fears Cuts' (*BBC News*, 22 December 2016) <<https://www.bbc.co.uk/news/uk-wales-politics-38385381>>. The *Framework* indicated that a number of disabled adults were living in care homes, although neither the number of working age adults in this position nor the number of individuals who did not wish to be living in such an arrangement was stated. The document states, simply, that in the year 2011-2012 111,800 adults 'were supported either in the community or in care homes', of whom 28,900 were aged 18-64. Page 45.

Equality was frequently directly referenced⁷⁶ and certain of these references were strongly articulated. For example:

We must strive to create an environment in which disabled people have access to the same opportunities as everybody else....⁷⁷

In addition, the case studies in the *Framework* created an intrinsic sense of equality and 'sameness' with non-disabled people.

Equality also appeared as an implicit theme.⁷⁸ It was often connected to the narratives of personal and social agency. For example:

The key message is that buildings and public spaces, as well as access to the countryside, should be designed for everyone to use – this promotes equality, sustainability and value for money. Physical access barriers limit the choices that people have in their everyday life – where to shop, where to go to school, where to meet friends.⁷⁹

However, as discussed above, there was an inconsistency in the *Framework*, in which the *stated* commitment to equality of personal agency contrasted with a latent sense of inequality, or distinction, between those requiring social care support and those not in need of such support. This was reinforced by a lack of a sense of equality in the sections relating to social care. In the *Framework*, equality was not explicitly envisaged as a product of social care support (see the discussion in section 3.4 below). It was instead typically connected with access and seen to flow from access. For example:

⁷⁶ There were 34 passages that made explicit reference to equality and a further 18 references to specific equality strategies, plans and legislation.

⁷⁷ Page 4.

⁷⁸ In particular, there were 20 references to 'all people' or 'everyone' or similar, six of which conveyed a clear sense of equality within their context. For example, 'Progress requires action that is ... very local and specific, such as how local services are delivered, the design of shopping centres, pavements and bus-stops, access to banks and pubs, and ensuring that surgeries, schools and colleges are inclusive and welcoming to all' (page 31). The narrative of social agency in the *Framework* also conveyed a sense of equality – see Section 3.2.

⁷⁹ Page 58.

Access to the natural environment enables disabled people to have the same choices for leisure and holidays as everyone else.⁸⁰

Like inclusion, equality was expressed as a central but often generalised vision that carried no strong sense of what was envisaged for disabled people. For example:

[The *Framework*] builds on the specific priorities identified by disabled people and sets out how we will address the barriers to equality.⁸¹

Other passages were more specific. Equal opportunities and ‘sameness’ between disabled and non-disabled people were particularly articulated,⁸² although one extract constructed disabled people as ‘different’.

...children can learn very early in life to see *others* who are *different* as equal, and it is better to learn this from direct *exposure* rather than as part of the curriculum’ (emphases added).⁸³

Rights were also commonly referenced in the *Framework*.⁸⁴ As with the earlier Welsh Government documents, there were various references to rights in the form of entitlements under certain pieces of legislation or in particular contexts, such as tenants’ rights, or rights to advocacy, information or healthcare.⁸⁵ Rights were also expressed as an inherent part of the human condition,⁸⁶ on occasion attached to specific elements of the independent living counter-narrative, such as the right to self-determination:

⁸⁰ Page 58.

⁸¹ Page 5.

⁸² For example: ‘Transport enables disabled young people to become more independent, including getting to work and going to the pub and the cinema with their peers’ (page 57).

⁸³ Page 65.

⁸⁴ Across the document there were 29 references to rights, including eight to rights emanating from the UNCRPD and one reference in a case study. There was also discussion of the UN Convention on the Rights of the Child – a convention by which the National Assembly for Wales and the Welsh Government are explicitly bound (see Chapter 9).

⁸⁵ There were eight such references.

⁸⁶ For example, ‘The Framework demonstrates that tackling barriers for disabled people will not only advance their rights, it will have wider benefits in terms of access and inclusion, and will promote more sustainable and responsive services for all.’ (Page 4).

The Framework respects the rights of individuals to have freedom of choice in how they live their lives, and helps support the rights of disabled people.⁸⁷

Overall, however, rights were not expressed – as in the texts from the DPM datasets – as integral to independent living. In particular, there was little discussion of independent living as a right in itself. Other than the brief – and problematic – discussion of Article 19 outlined in Section 2 above, the notion of independent living as a right was confined to the statement that the intended outcome of the *Framework* was:

An enabling society in which disabled children and adults enjoy the right to independent living and social inclusion.⁸⁸

This was a direct contrast with the texts from the disabled people's movement, in which independent living was directly, strongly and consistently expressed as a right in itself and indivisible from disabled people's wider human and civil rights.

3.4 The enablers of independent living

In the texts from the Anglo-British disabled people's movement the most important enablers were direct payments and personal assistance. These were expressed as fundamental to independent living and as the means for disabled people to translate their self-determination into the lived experience, and were central to discussion of the transference of control from the state to the individual. Access was also strongly present, explicitly and implicitly. More collectivist responses, including peer support – particularly that offered by CILs – and co-production, were also discussed. It was in discussion of the enablers of independent living that the greatest differences appeared between the Welsh and the Anglo-British documents. In the Welsh DPM texts access was referenced most frequently. In terms of social care, less emphasis was placed on direct payments and almost none on personal assistance. Overall, the Welsh texts demonstrated a particular interest in collective approaches and

⁸⁷ Page 8.

⁸⁸ Page 17.

suggested an interest in exploring ways of enabling independent living that depended more on involvement in democratic processes rather than individual control of resources.

In the *Framework* access was strongly positioned as the core enabler of independent living. Overall the document was largely concerned with access in various forms and generally read as a strategy for implementation of the social model, which was both directly and indirectly referenced.⁸⁹ Access permeated the document and underwrote the narratives of personal and social agency, particularly the latter.

Many disabled people rely on public transport to get to work and participate in family and community events, and for access to leisure, culture and public services. Barriers still exist which prevent independent mobility, contributing to the isolation and exclusion of many disabled people.⁹⁰

Access was explicitly referenced in seven of the nine intended outcomes listed in the *Framework*.⁹¹ It was related both to specialised fields, such as independent advocacy⁹² or adapted housing,⁹³ and to universal elements, such as the built environment and public places.⁹⁴

It is stated in section 2, above, that social care was relatively briefly addressed in the *Framework*, and the forthcoming legislation was seen as the core means of connecting social care to independent living. Both sections on social care placed a strong focus on direct payments. The number of people using direct payments was

⁸⁹ See Section 2, above.

⁹⁰ Page 52.

⁹¹ In the *Framework* outcomes, access was referenced in those relating to information and advice, advocacy, appropriate housing, person-centred technology, public transport, the wider environment and CILs. The full statements of outcomes that related to access were: 'having access to good quality and accessible information and advice', 'improved access to independent advocacy services', 'improved access to adapted and accessible housing', 'having access to technology that supports independent living', 'better access to public transport', 'improved access to buildings, streets and public places' and 'an increase in the number of disabled people having access to a Centre for Independent Living in Wales'. The outcomes that did not cite access were: 'having more control over their lives by being able to make choices in the care and support they receive' and 'increased employment rates for disabled people'. Note that access is similarly integral to many of the 12 pillars of independent living. See Chapter 2, section 4.

⁹² Page 19.

⁹³ Page 20.

⁹⁴ Page 25.

cited as a means of measuring the progress of the *Framework*,⁹⁵ and there was discussion of a need to promote, facilitate and expand the scope of these. In the earlier Welsh Government texts direct payments had been established as a form of 'repository' for specific fragments of independent living, particularly those to do with personal agency. This was echoed in the *Framework*. Direct payments were recognised as being a central means of enabling people to obtain and control their own support and the qualification of the fragments of choice and control was mitigated where direct payments were under discussion.⁹⁶ However, the support to be purchased by direct payments remained typically envisaged as 'care' and 'services',⁹⁷ with only one reference to personal assistance.⁹⁸

Both sections of the *Framework* that discussed social care were characterised throughout by the depiction of individuals as users of services, rather than individuals with lives of their own. The qualification of the elements of personal agency where social care support was under discussion, and the prevalence of the idea of voice are explored in section 3.1, above, but despite this, the narrative of personal agency still appeared more strongly than that of social agency in these sections. Other than the allusions to people 'going out more' and having 'direct control over how they spend their day', cited in section 3.2 above, and a statement that social care support 'is essential to enable [people using support] to carry out everyday activities', there was no indication of the purpose of support in terms of achieving a meaningful life. Overall, control or influence were typically seen to be exerted over support itself

⁹⁵ Page 17.

⁹⁶ See discussion in section 3.1 above, and footnote 47.

⁹⁷ For example: 'The scope of direct payments also needs to be extended, to assist individuals to have more control over the design of the care package and services they receive ...'. Page 46. In Section 4.3 there were six references to 'care' and eight to 'services' with four references to 'support'. Section 3.4 contained only one reference to services, seven to 'care' and five to 'support', all of which occurred in the phrase 'care and support' which was the phrase used in the forthcoming Bill. There was also one further reference to individuals having support in decision-making.

⁹⁸ 'Direct payments are one route to promoting this ethos. They mean that, following assessment, people can opt to have a cash sum which they use to buy the kind of support they want, e.g. by employing a personal assistant. This can be very empowering, enabling people to go out more rather than stay at home to receive traditional forms of care, and giving them direct control over how they spend their day and how and when services are provided.' Page 46. (This extract is discussed in section 3.2, above.) There were two other references to personal assistance in the document. One stated: 'DEWIS, based in Pontypridd, provides a range of services to enable disabled people to access direct payments, to arrange their own support and to manage their personal assistants.' Page 35. The other occurred in a discussion of the creation of a guide for 'Direct Payments Employers' to focus on the relationship between the employer and the PA. Page 21.

(typically in the form of ‘services’) rather than any ensuing activity. There was also very limited discussion of how individuals *not* in receipt of direct payments would use social care to achieve independent living or how ‘care’ or ‘services’ purchased through direct payments would enable personal or social agency. Take up of direct payments is low in Wales compared to England,⁹⁹ yet the *Framework* contained no detailed discussion as to how this might be improved, or how the principles of independent living could be incorporated into other support structures.¹⁰⁰

Cooperation and co-production were also expressed as central enablers of independent living. Along with ‘choice and control’, the remaining three ‘core values’ set out in the section on vision in the document were:

Confidence – empowered disabled people working constructively with public, voluntary and private organisations to achieve better outcomes;

Co-operation – effective coalitions and organisations of disabled people, sharing good practice, collecting evidence of problems and giving individuals a stronger voice;

Co-production – disabled people working in partnership with public services and the private sector to identify problems and solutions, tackle delivery issues, and maximise opportunities for improvement.¹⁰¹

Examples of co-production in the document included the promotion of the ‘involvement of disabled people in designing and planning local services’,¹⁰² working

⁹⁹ Correspondence from the Auditor General for Wales to the Chair of the Public Accounts Committee (2 March 2016)

<<http://www.senedd.assembly.wales/documents/b10265/Social%20Services%20and%20Well-being%20Wales%20Act%202014%20correspondence%20from%20the%20Auditor%20General%20for%20Wales%20t.pdf?T=9>> accessed 12 April 2018. For recent figures of the numbers of people receiving different forms of assistance, see StatsWales, ‘Adults Receiving Services by Local Authority and Age Group’ (undated) <<https://statswales.gov.wales/v/FR1W>> accessed 31 July 2019.

¹⁰⁰ In relation to options other than direct payments, discussion of the forthcoming reform of social services legislation referred to an outcomes-focused approach to assessment and eligibility decisions, new duties relating to the individual’s wellbeing, a new model of citizen-directed support, and the portability of support packages across local authority boundaries, but these were not explored.

¹⁰¹ Page 14.

¹⁰² Page 11.

with local DPOs to identify need, problems and solutions,¹⁰³ and the role of DPOs – with others – in providing a ‘strong collective voice’ in engagement with the public sector.¹⁰⁴ Centres for Independent Living were seen as having a central role in co-production, and were presented as ‘delivery partners’ of independent living.¹⁰⁵ CILs were also identified as support mechanisms for disabled individuals, and an increase in the number of people with access to a CIL was listed as an intended outcome of the document.¹⁰⁶ Resources to facilitate this were not committed, although it was stated that CILs might benefit from the requirement in the forthcoming social care legislation that local authorities promote the development of ‘social enterprises and cooperative solutions’.¹⁰⁷ However, despite a recommendation from Mark Drakeford that ‘Welsh Government should make it a requirement that in each Local Authority there would be at least one co-operative-based direct payments provider’¹⁰⁸ there was no significant discussion of the potential pooling or collective use of direct payments, and only two references to citizen-directed support. Neither of these connected CDS with direct payments or explored CDS in any depth, and both indicated that CDS would be achieved by the forthcoming legislation.

4. Different forms of independent living and the language of ‘independence’

This thesis has demonstrated that the language use around independent living was critical. Chapter 8 demonstrates that the use of the language of independence drew the counter-narrative of independent living towards master narratives of individual self-reliance that were particularly damaging to the disabled people’s movement, requiring the movement to accomplish a form of linguistic reclamation in which narratives of self-reliance were rejected in favour of those of self-determination. Chapter 9 demonstrates that in the Welsh Government policy documents prior to the

¹⁰³ Page 31.

¹⁰⁴ Page 34.

¹⁰⁵ Page 30.

¹⁰⁶ Page 30.

¹⁰⁷ Page 30.

¹⁰⁸ Mark Drakeford, ‘Framework for Action on Independent Living Consultation Response’ (20 December 2012) <<https://www.markdrakeford.com/en/independentlivingconsultation/>> accessed 2 August 2019.

Framework 'independence' had a fluid meaning that pertained more to self-reliance than to self-determination. This section examines how the phrase 'independent living' and the language of independence were used in the *Framework*, and the implications of this for the counter-narrative.

4.1. The language of 'independent living'

The definition of independent living provided in the *Framework* is explored in Section 2, above. Despite the existence of this definition, there were a small number of references to independent living in the *Framework* that constructed it in ways that were distinct from this definition and the counter-narrative of the disabled people's movement. The definition of independent living itself indicated that the phrase 'independent living' should be used in two distinct ways, one of which related to 'an approach to service provision'.¹⁰⁹ A further reference equated independent living to service models – and linked this to resource implications:

- at an individual level there is substantial qualitative evidence... suggesting that independent living provides significantly more benefits than conventional forms of service provision.
- at service delivery level, several published evaluations highlighted the reduced costs involved in the delivery of Independent Support mechanisms.¹¹⁰

It therefore appeared that the Welsh Government had not yet fully understood the existence of independent living as a series of outcomes related to personal and social agency, rather than a particular approach to 'services' or support.

¹⁰⁹ The relevant passage reads: 'In this document the term 'independent living' is used in two ways: to express the aspirations of disabled people as set out above; to describe an approach to public service provision that supports and empowers this aspiration'. Page 7.

¹¹⁰ Pages 9-10. The reference to 'Independent Support mechanisms' is not explained but appears to refer to mechanisms that support independent living. This extract comes from a section in the *Framework* entitled 'The business case for independent living'.

In addition, the *Framework* contained four references which explicitly or tentatively connected or constructed independent living with ideas of self-reliance. Three of these were references in discussions about employment to ‘independent living skills’, which related to the ability to carry out everyday tasks. For example:

Support for disabled young people should in the first instance focus on participation in mainstream education and training provision, and the enhancement of independent living skills.¹¹¹

This use of the phrase ‘independent living’ was connected to the master narrative of self-reliance, or self-sufficiency that the disabled people’s movement had rejected. It was almost never encountered, or was explicitly rejected, in the Anglo-British or Welsh DPM texts.¹¹²

The remaining reference used the term ‘independent living’ in line with the definition in the *Framework*, but connected this with a reduced need for services, conflating independent living with ideas of self-reliance. This extract, also cited above, states:

Public authorities should be encouraged to take a long-term view and recognise the benefits of independent living in terms of well-being for individuals, which can lead to less reliance on public services.¹¹³

There were therefore occasions within the *Framework* in which the phrase ‘independent living’ slipped into a construction that was not only distinct from the counter-narrative of the disabled people’s movement, but which related to the idea of self-reliance that was explicitly *rejected* in the texts from the movement.¹¹⁴ The texts

¹¹¹ Page 69.

¹¹² See, in particular, Debbie Jolly, ‘Personal Assistance and Independent Living’ (ENIL paper, 2010) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/jolly-Personal-Assistance-and-Independent-Living1.pdf>> accessed 10 November 2016.

¹¹³ This was stated to be one of the ‘main messages’ to come out of the consultation process on the *Framework*. Page 9.

¹¹⁴ There was also reference in the *Framework* to the ‘Welsh Government Independent Living Grant’ – a scheme which enabled minor adaptations to be made to properties which was piloted between 2011 and 2013 but discontinued. Welsh Government, ‘A Review of Independent Living Adaptations’ (2015) <<https://gov.wales/docs/caecd/research/2015/150123-review-independent-living-adaptions-en.pdf>> accessed 12 July 2018.

from the Anglo-British disabled people's movement had made it clear from the outset that independent living related to the ability to live a full life of one's choice *with the necessary support*, rather than living a life that was not 'relian[t] on public services'.¹¹⁵ Even in the *Framework*, therefore, the idea of independent living was both imperfectly understood, and connected to the idea of the lack of the use of support that the disabled people's movement was at pains to reject. It was certainly not yet understood as concept in which the use of support liberated rather than restricted.

4.2. The language of 'independence'

It is demonstrated in the preceding chapter that in the earlier Welsh Government policy documents, which drew heavily on those from Westminster, independence was both established as a central aim of social care support and, in cases, was explicitly deemed to refer to both self-reliance and self-determination. In the two documents prior to the *Framework*, however, independence was not expressed as a necessary value for social care support, and was indeed actively rejected. In the *Framework*, the inescapably integral connection between independent living and independence required the Welsh Government to accept independence as a positive concept, despite its potential collision with its own principles.

In the *Framework*, independence was certainly expressed as a vital outcome, with dependence framed as a negative:

Achieving a strategic shift from dependence and exclusion to independence and inclusion requires:...¹¹⁶

Indeed, in the sections on social care support, the *independence* of disabled people was referred to more frequently than independent living.¹¹⁷

¹¹⁵ Chapter 6, section 4.4.

¹¹⁶ Page 33.

¹¹⁷ In these two sections, there was one reference to independent living and two to independence.

In the *Framework* there was a certain level of conflation of the ideas of independent living and independence. For example, the title to one version of the *Framework* stated:

Framework for Action on Independent Living
Supporting disabled people to lead an independent life.¹¹⁸

Within the *Framework*, the word 'independence' was more commonly ambiguously used, or used to refer to self-reliance than it was used synonymously with independent living or to convey self-determination.¹¹⁹ Three of the references to self-reliance occurred in case studies and related to access, for example:

I have been to a building that the staff considered to be accessible because it had a ramp to the entrance, but what they didn't realise was that the ramp was too steep for most wheelchair users to push up it independently.¹²⁰

Of the ambiguous references in the *Framework*, independence was often placed adjacently to the idea of self-determination or fragments of the independent living counter-narrative.

The ethos which underpins the Welsh Government's reforms of social services is that services should:... promote independence and autonomy....¹²¹

This created a link between the ideas but did not exclude the idea of self-reliance.

¹¹⁸ This appears on the title page of the Word version of the *Framework*, but not in the PDF version.

¹¹⁹ Independent living and self-determination are two separate concepts. In the *Framework*, references to independence in the form of either were coded together in this exercise as the aim was to establish the distinction between references to independence as self-reliance (or the master narrative) and references to independence that inclined towards the exercise of linguistic reclamation attempted by the disabled people's movement (or the attempts to establish a counter-narrative of independence). Eleven references related to or implied self-reliance while six were connected to self-determination or independent living. There were 11 ambiguous references.

¹²⁰ Page 47.

¹²¹ Page 46. There were five such references.

Within the *Framework*, therefore, the language of independence was unclear, and commonly used to refer to the construction that had been explicitly rejected by disabled activists.

5. Discussion

By the advent of the *Framework* it was clear that the Welsh Government had grasped that independent living was a specific concept encompassing a series of ideas that were central to the disabled people's movement and which required a shift in certain existing narratives. It had also understood that it was itself subject to certain legal obligations related to independent living under the UNCRPD, although these were not accurately reproduced. These understandings placed the Welsh Government in a quandary. While some elements of independent living were clearly adjacent to its own policy principles – all of which were frequently referenced in the *Framework* – the Welsh Government was also required to confront and incorporate colliding ideas, including the idea of independence itself. In addition, the sense of individualism that was central to independent living had already been explicitly rejected by the Welsh Government but could not be easily ignored in or excluded from the *Framework*.

There was no doubt that the narratives of personal and social agency were both conveyed in the *Framework*, which generally constructed disabled people as individuals entitled to lead their own lives on an equal basis to others. Overall, the document successfully refuted master narratives of passivity, helplessness, deficit and othering. In particular, the strongly collectivist approach of the social model and the connected matter of access were prominent. It is noted in Chapter 8 that the social model is more closely aligned with the Welsh Government public sector policy principles than independent living,¹²² and this was reflected in the *Framework*. Where the independent living counter-narrative ran into trouble, however, was where individuals required support from the public sector in the form of social care. Here the component narratives and fragments of independent living were modified,

¹²² Section 2.1

appearing in a construction that was partial and compromised and which ran counter to the stated message of equality found elsewhere in the document. The individualism inherent in independent living was therefore welcomed and even lauded, *as long as the public sector was not involved*.

Essentially, where public sector support was under discussion the Welsh Government appeared unable to reconcile the inclination towards individualism emerging from the disabled people's movement with its own predisposition towards communitarian approaches. The 'siphoning off' of central ideas to direct payments that occurred in both the earlier documents and the *Framework* was a means of obscuring this collision and indicating support for principles of individualism while 'containing' these principles within one particular enabling mechanism. Overall, however, even where direct payments were under discussion in the *Framework*, the Welsh Government both reverted to its own policy priorities and diminished those of independent living, reducing the status of those needing assistance in daily life as individuals and constructing them primarily in relation to their role as users of social care support. The result was a *reinforcement* in these sections of master narratives of deficit and otherness, relating not to disabled people overall, but to those who were 'reliant on specific support'¹²³ from the public sector. The inequalities of outcomes, in relation to both personal and social agency, for this group resulted in those with the most severe impairments remaining 'othered' and subject to an external agenda that restricted individual agency. Rather than explore whether and how the ideals of the disabled people's movement could be developed within or alongside those of the Welsh Government, this matter was elided. This was not to say that this was the *intention* of the document. It was more likely that this distinction had arisen as an inadvertent outcome of the difficulty faced by the Welsh Government in integrating colliding principles.

The modification of the narratives of personal and social agency, and the ensuing damage to the idea of equality was likely also to be due to the facts of limited finances and the impracticality of a government creating policy that offers relatively unconditional access to public resources. A general silence on the latter of these

¹²³ Page 4.

aspects in the Anglo-British DPM texts is discussed in Chapter 6, section 4.4 of this thesis, where it was noted that this created a potential weakness in the counter-narrative. The twin difficulties of the financial climate of austerity and the inability of a government to offer a 'blank cheque' together created a significant hurdle to the inclusion of an effective vision of independent living where public sector policy was concerned. As with the difficulty of conflicting policy principles, the Welsh Government demonstrated a reluctance to engage with this dilemma directly. There were certainly allusions to the potential impact of resource constraints – framed as a circumstance externally imposed by the UK government¹²⁴ – but no discussion of how principles of independent living could be enabled within this climate where individuals received social care support.¹²⁵ There were hints in the *Framework* that the Welsh Government was seeking to develop collaborative and collective approaches to independent living that might better reflect its own policy principles. These were most obviously seen in the references to co-production, 'confidence' and cooperation. However, the generally hazy and aspirational discussion of these, and the lack of specific resources to support such efforts undermined their potential. In addition, there was no obvious interest in the development of a 'Welsh' model of independent living that spoke to the values of the Welsh Government communitarian narrative.

More effectively deployed within the *Framework* were the fragments of the independent living counter-narrative that were adjacent to the principles of the Welsh Government. The high number of references to certain adjacent fragments suggested that the Welsh Government was finding significant value in emphasising principles that were apparently common to government and grassroots narratives. In particular, the strong referencing of 'wellbeing', which appeared a similar number of times to control, indicated that independent living was being intentionally aligned with the Welsh Government's own policy principles. To an extent, the 'sharing' of certain fragments between the disabled people's movement and Welsh Government

¹²⁴ It is stated above that one of the aims of the *Framework* was stated as: 'to set out a positive vision for disabled people in Wales in the challenging context of recession and the UK Government's programme of welfare reform, combined with public expenditure cuts'. Page 7. See also discussion on page 5 of the *Framework*.

¹²⁵ There was, for example, no direct acknowledgement that those receiving social care support would be in a particularly difficult position compared to others under the austerity regime, or discussion of which principles or outcomes should be prioritised in the difficult financial circumstances.

reduced their power. This was particularly true of equality. The various references to equality documents, strategies, and legislation on occasion framed equality not as an aim in itself, of vital importance to disabled people, but as a target and obligation for the Welsh Government, connected to the fulfilment of administrative objectives. In addition, the general imprecision of the expression of certain adjacent elements, particularly inclusion, rendered these ideas amorphous and less powerful than in the texts from the disabled people's movement. This enabled the Welsh Government to indicate support for the counter-narrative while remaining vague about implications and outcomes. Again, this was most clearly exhibited in the discussion of equality, which was *explicitly* cited as a core principle, but *implicitly* contingent on a lack of need for social care support. As a result, inequality between those needing and those not needing social care support increased rather than decreased in the document.

The construction of independent living in the *Framework* also suffered from imprecision around the language of 'independence' and of independent living itself. There is discussion in the preceding chapter of the conflicted approach to independence exhibited by the Welsh Government around the time of the development of the *Framework*. While independence had initially been incorporated – as a central principle – in social care policy, the Welsh Government had since attempted to reject it as a concept connected with individualism and isolation.¹²⁶ The language of '*independent* living' therefore again forced the Welsh Government onto uncomfortable ground. Two things occurred. Firstly, independence was re-introduced and positioned as a positive value, including in relation to social care. Secondly, and in contrast, there was a failure to understand or to make the critical distinction between self-determination and self-reliance that was necessary if master narratives of independence were to be rejected. Indeed, in the *Framework*, not only was independence frequently expressed as self-reliance, but independent living *itself* was equated with this value.

It is stated in Chapter 8, section 3.2 that if independent living was to be released from master narratives that equate independence with self-reliance, the critical

¹²⁶ See Chapter 9, 3.

distinction between self-reliance and self-determination articulated by disabled activists and the predication of independent living upon the latter needed to be not only fully understood but also *reproduced* in policy. In the Welsh context the *Framework* demonstrated that the attempt by the disabled people's movement to reclaim 'independence' from its master narratives of self-reliance had not yet been successful. The connection of independence, and even independent living, to the idea of self-reliance indicated that the counter-narrative was highly susceptible to becoming re-aligned with master narratives that activists had so strenuously resisted and which were potentially deeply damaging to disabled people. In Welsh Government policy a gap of *both* understanding and intention existed in relation to independent living that had grave implications for the effectiveness and impact of the counter-narrative.

6. Conclusion

In terms of the successful refutation of the master narratives identified by the disabled people's movement and the absorption of the counter-narrative of independent living into policy, the Welsh Government's pivotal document was only partially successful. While there was expression of a new disabled identity, the values of independent living were strongly compromised where the principles of individualism collided with those of the Welsh Government itself. In sections in which social care was under discussion, the fragments of independent living were undermined and master narratives were essentially reproduced. Where social care was concerned, the *Framework* also largely shifted responsibility for enabling independent living to the then forthcoming social care legislation. The following chapter examines certain central provisions of this legislation to establish whether and how fragments of independent living are included within them, and how successfully the legislation expresses independent living as a counter-narrative and challenges the master narratives that it was designed to resist.

Chapter 11: The Social Services and Well-being (Wales) Act 2014

1. Introduction

This chapter explores the Social Services and Well-being (Wales) Act 2014 ('the Act') and attendant regulations and guidance. The study of law was important in this thesis for three reasons. Firstly, the case study examined in this thesis is that of independent living in the context of Welsh Government policy on disability and adult social care. In discussions around the *Framework for Action on Independent Living* ('the *Framework*'), the Welsh Government identified the Act as a central tool through which social care in Wales would contribute to or enable independent living.¹ For reasons of completeness, the Act therefore required study. In addition, the Act was the biggest development in social care policy in Wales since devolution. It was the first major welfare statute to be enacted under the Assembly's increased law making powers, and the first with a 'sister statute' at Westminster. It therefore created a unique opportunity for the Welsh Government not simply to reform social care, but to construct its distinctive public sector principles in law and to consider its approach to those using social care. Social care law in England and Wales has historically comprised statutes that have been criticised by the disabled people's movement for their perpetuation of narratives of deficit and dependency.² The Act therefore shed particular light on how far the Welsh Government was inclined or able to repudiate these narratives, and how it sought to deal with points of collision and adjacency between its own principles and those of independent living.

¹ See Chapter 10, section 2.

² See Chapter 4, section 4. Among others, Oliver argued that the National Assistance Act 1948 and the Chronically Sick and Disabled Persons Act 1970, reinforced structures of helplessness and dependence. Mike Oliver, 'Disability and Dependency: A Creation of Industrial Societies?' in Len Barton (ed) *Disability and Dependency* (Falmer Press 1989), citing A Shearer (original source not provided).

Secondly, law has a distinct purpose and a particular impact in the policy context, creating *actionable* legal entitlements and duties. This is not to say that these are necessarily unambiguous – multiple aids are available to enable judges to interpret the meaning of statute³ and there are many examples of poorly drafted legislation.⁴ However, the binding nature of the obligations and entitlements created through law is distinct from the content of policy documents that set out ambitions and expectations. As a result, a government’s policy commitments are likely to be, to some extent, clarified in legislation, particularly where public resources are in issue. In addition, law is crafted in a wholly different way from policy – it is required to pass through the legislative process, under the guidance of a Minister,⁵ with amendments sought by backbench and opposition AMs. The legislative process therefore introduces unique opportunities for non-governmental priorities to be introduced to a Bill, although these typically require government acceptance to pass. This contrasts with the policy process, where there is greater governmental control.⁶

Finally, to understand the impact on a counter-narrative of its involvement in state policy, it is important to examine how the narrative is treated where there are competing priorities. It has already been stated that the Act, together with the *Framework*, created a particular opportunity for the Welsh Government to incorporate the outcome of independent living for disabled people into policy. However, the *Framework* and the Act are very different creatures. The *Framework* was devised and developed by the Welsh Government in tandem with DPOs, third sector disability organisations and other agencies *expressly* to bring independent living and the UNCRPD into Welsh Government policy and to demonstrate how independent living could be supported by actors in multiple fields. The purpose of the

³ See, James Holland and Julian Webb, *Learning Legal Rules: A Student’s Guide to Legal Method and Reasoning* (9th edn, OUP 2016), Chapter 9.

⁴ A notorious example in England and Wales is the Dangerous Dogs Act 1991, frequently cited as an example of legislation that was ‘rushed through’ Parliament in response to a series of incidents that gained extensive media attention. See, Christopher Hood, ‘Assessing the Dangerous Dogs Act: When Does a Regulatory Law Fail?’ [2000] PL 282.

⁵ Certain bills – such as those introduced by AMs through the ballot process, rather than from the Welsh Government’s legislative programme – may not have the guidance of a Minister. This did not pertain to the Social Services and Well-being (Wales) Bill.

⁶ In addition, policy, including legal guidance, may be developed by a small number of civil servants with limited ministerial input.

Act was to re-organise and reform legislation around social care.⁷ The Act therefore gave the opportunity to examine what may happen to a counter-narrative on incorporation into state discourse where it is recognised as one intended outcome, but is not itself the primary purpose or even a priority for policy makers. One essential question was therefore whether the commitment to independent living would 'hold' and remain rooted in this less fertile policy ground.

One core aspect of this situation was that disabled activists had less ability to influence the construction and development of the Act. Disabled activists were certainly engaged in lobbying around the Act, regulations and guidance, providing responses to consultation documents and evidence to the Health and Social Care Committee ('the H&SC Committee'), which scrutinised the Bill. Various of the Welsh DPM dataset texts were drawn from these responses. In addition, the H&SC Committee sought information directly from 'service users', and a number of third sector organisations established an advisory group to support the Committee's work.⁸ The Welsh Government itself considers that the 2014 'statutory framework' was 'co-produced' with stakeholders.⁹ There is, however, no evidence that the Act was developed in the close contact with DPOs that had existed in the development of the *Framework*. Indeed, given the scope of the Act and the actionable quality of legislation, such close contact would be unlikely. As noted below, the Act also adjusted, rather than re-developed, a pre-existing social care structure. It therefore

⁷ It is worth noting here that the significant majority of users of social care are people over working age who require support as a result of physical or cognitive impairments that typically arise in later life. However, across the UK, a significantly higher amount of resources per head are allocated to working age disabled people. In relation to England, The Kings Fund states, 'Local authorities now spend nearly as much money on long-term care for working-age adults as for older people'. Simon Bottery, Deborah Ward and Deborah Fenney, 'Social Care 360' (*Kings Fund*, 26 April 2019) <<https://www.kingsfund.org.uk/publications/social-care-360>> accessed 31 July 2019. In Wales in the year 2017-2018, the net local authority social services spend on people aged 65 and over was £585,872, with £613,206 spent on adults aged under 65. This figure was not broken down according to type of expenditure. StatsWales, 'Social Services Revenue Outturn Expenditure Subjective Analysis by Authority' (undated) <<https://statswales.gov.wales/Catalogue/Local-Government/Finance/Revenue/Social-Services/socialservicesrevenueexpendituresubjectiveanalysis-by-authority>> accessed 31 July 2019.

⁸ National Assembly for Wales Health and Social Care Committee, Social Services and Well-being (Wales) Bill: Stage 1 Report, (July 2013) para 6.

⁹ Welsh Government, 'The Co-Productive Approach Taken to Develop the Statutory Framework for the Social Services and Well-being (Wales) Act 2014: Qualitative Research with Welsh Government Stakeholders' (May 2017) <<https://gweddill.gov.wales/docs/caecd/research/2017/170510-co-productive-approach-develop-statutory-framework-social-services-well-being-act-2014-en.pdf>> accessed 17 May 2019.

gave less scope for disabled activists successfully to promote radical or new solutions. In general, therefore, the disabled people's lobby had less ability to influence the construction of the legislation, and a more 'diluted' voice.

2. The history and structure of the Act and the provisions selected for examination

A brief history of the Act is provided in Chapter 3, section 6.1. It states that a core impetus for the reform of social care legislation was the investigation by the Law Commission that took place between 2008 and 2011. In Wales the report and recommendations of the Law Commission created an opportunity for the Welsh Government to establish its own legislative identity and develop a social care system that reflected its own principles. The Act was certainly intended to implement the policy set out in the 2011 white paper, *Sustainable Social Services for Wales*, discussed in Chapter 9, which had a strong focus on the Welsh Government communitarian narrative.¹⁰ As a result the Welsh Act differs from the Care Act 2014 – the social care legislation passed contemporaneously in Westminster for the English context – and creates a distinctive social care system in Wales. In particular, the Welsh Government chose not to incorporate personal budgets – the mechanism implemented in England as a cornerstone of the Westminster narrative of 'personalisation',¹¹ and requires local authorities to promote social enterprise, cooperatives and user-led services,¹² rather than a 'market' in support.¹³ A safeguarding power to enter a person's home – rejected in England – was included in the Welsh legislation,¹⁴ and the Act applies to children as well as adults, including

¹⁰ See Chapter 9. This white paper included a statement that social care 'is a public service for Wales and we expect it to be based on our Welsh public services values'. Welsh Assembly Government, 'Sustainable Social Services for Wales: A Framework for Action' (2011) <<http://gov.wales/docs/dhss/publications/110216frameworken.pdf>> accessed 23 February 2018, para 1.2.

¹¹ See Chapter 3, section 6.1 and Chapter 9.

¹² Section 16.

¹³ Section 5 of the Care Act 2014 imposes a duty on local authorities to promote 'the efficient and effective operation of a market in services'.

¹⁴ Section 127 creates a power for a local authority to obtain an order that enables them to speak in private with a person believed to be at risk in order to ascertain whether he or she is making decisions freely and is at risk. This may include the power to enter a specified premises.

matters of adoption and looked after children. Similarities with the Care Act 2014 include an extension of the Act to carers as well as those in need of support, and a strong focus on services that prevent needs for support arising or increasing.

Although the Act demonstrated a move away from principles that were becoming established in social care in England, it cleaved to a Westminster heritage. The remit of the Law Commission was to examine and make suggestions for the reform of social care law as it had developed in England and Wales over some 60 years, not to overhaul its underlying political and social narratives.¹⁵ The Act was therefore developed out of the historic and controversial legislation noted above, and more modern legislative developments that reflected the Westminster principles of individualism and marketisation.¹⁶ Short of a complete re-development of social care structures, which the Welsh Government did not have the capacity to undertake,¹⁷ the Act inevitably therefore looked ‘backwards’ as well as ‘forwards’, and was constructed in a context in which there was direct collision between the counter-narrative of independent living and former legislation; and between the public sector principles espoused in Westminster and those in Wales.

The Act comprises 11 parts, which include general functions, assessment, meeting needs, charging, safeguarding and complaints. Regulations have been implemented in various areas, including assessment, eligibility, direct payments, care planning and the choice of accommodation. Guidance has been issued in the form of Codes of Practice, each of which is relevant to a specific Part of the statute.¹⁸ All these are underpinned by a central duty on those acting under the Act to ‘promote the well-being of people who need care and support’.¹⁹ Further ‘overarching duties’ are also

¹⁵ Law Commission, *Adult Social Care: A Consultation Paper* (Law Com Consultation Paper 192, 2010).

¹⁶ For example, the National Health Service and Community Care Act 1990 followed the publication of the white paper which set out a number of reforms including the development of community care and a mixed economy of care. Department of Health, *Caring for People* (Cm 849, 1989).

¹⁷ The restrictions on the Welsh Government in terms of policy development are discussed in Chapter 3.

¹⁸ For documentation around the Act see, Welsh Government, ‘Care and Support in Wales is Changing’ (last updated 24 August 2017)

<<https://gweddill.gov.wales/topics/health/socialcare/act/?lang=en>> accessed 31 July 2019.

¹⁹ Section 5. ‘Well-being’ is defined in section 2.

created.²⁰ Every provision of the Act, and all actions carried out under it must therefore be read and considered in the light of these duties.

The provisions of the Act that were studied for this thesis were those that were particularly illustrative of the intersection of independent living and the Welsh Government communitarian narrative and the matter of adjacency or collision. These were statements that related specifically to independent living – including references to the UNCRPD and the social model of disability, provisions that related explicitly to the independence of those using social care, the wellbeing duty, and the treatment of direct payments. The statements relating to independent living, the UNCRPD and the social model were clearly of importance, and provisions relating to independence had to do with the linguistic reclamation of independence discussed in Chapter 8. Wellbeing has been identified in this thesis as a principle that is adjacent to elements of independent living.²¹ As the underpinning duty of the Act, it also formed the context within which the counter-narrative of independent living needed to be realised. Direct payments have been identified in this study both as a core enabler of independent living and a ‘repository’ in Welsh Government policy of various ‘troublesome fragments’ of the independent living counter-narrative. These areas were not the only provisions of the Act that potentially enabled independent living or gave scope for the narrative reconstruction of identity and agency of those using social care, but for reasons of space it was possible to select only a small portion of the Act for study in this project. This analysis of the Act is therefore contingent on the sections that were selected for examination.

The analysis comprised a doctrinal analysis of relevant provisions of the statute, as supported by the Regulations and guidance and supporting documentation. Because particular provisions were selected for study, rather than the whole statute, the discussion sections in this chapter follow the statements of findings relating to each provision. A further discussion section is presented at the end of the chapter, which draws together some common themes.

²⁰ Section 6.

²¹ Chapter 8, section 2.2.

3. Independent living in the Act

In 2012, the Joint Committee of Human Rights in Westminster argued that any forthcoming legislation on social care should embed independent living (in the form of Article 19 of the UNCRPD) in domestic legislation.²² During the passage of the Bill, DPOs and other organisations argued that enjoyment of the right to independent living, the social model of disability²³ and the UNCRPD²⁴ should all be placed on the face of the Act. In particular, there were suggestions from various organisations that independent living should be incorporated into the wellbeing duty (discussed in Section 5, below),²⁵ and that there should be greater connection between the Act and the *Framework*.²⁶ Despite this lobbying, the recommendation of the Joint

²² Joint Committee on Human Rights, *Implementation of the Right of Disabled People to Independent Living* (2010-12, HL 257, HC 1074), para 65 and recommendation 7. This recommendation pertained to England, but had persuasive power in the Welsh context, particularly as it was the investigation of the Joint Committee that – together with the development of the Disability Wales ‘Independent Living Now!’ campaign – led to the development of the Welsh Government *Framework for Action on Independent Living*. See Chapter 3, section 6.2 and Chapter 10.

²³ See responses to the Bill from Disability Wales on behalf of Partner Organisations (March 2103), Diverse Cymru (undated) and Mind Cymru (undated). All available at National Assembly for Wales, ‘Social Services and Well-being (Wales) Bill: Consultation responses’ (undated) <<http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?Id=5961>> accessed 21 July 2019.

²⁴ In written responses to the Bill, Scope Cymru argued that there should be ‘a general acknowledgement on the face of the Bill that well-being, and particularly its defining components, should be understood as defined under the [UNCRPD].’ The organisation Children in Wales stated that the Bill needed to ‘cross reference’ other relevant legislation, including the UNCRPD. The advisory group on the Bill argued that the Explanatory Memorandum to the Bill needed to deal with the matter of ‘adherence to relevant UN Conventions and principles’, including the UNCRPD. All available at National Assembly for Wales, ‘Social Services and Well-being (Wales) Bill: Consultation responses’ (undated) <<http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?Id=5961>> accessed 21 July 2019.

²⁵ In written responses, Disability Wales (for partner organisations) argued that the ‘enjoyment of the right to independent living’ should be incorporated into the meaning of wellbeing. Diverse Cymru argued that there was ‘a need to explicitly reference independent living within the definition of wellbeing’. A partner response by the Welsh Alliance for Citizen-Directed Support, the Direct Payment Support Schemes Network and Wales Disability Reference Group (attached to the response of Mind Cymru) also suggested that a right to independent living should be included in the meaning of wellbeing. All available at National Assembly for Wales, ‘Social Services and Well-being (Wales) Bill: Consultation responses’ (undated) <<http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?Id=5961>> accessed 21 July 2019. This was also stated by Disability Wales in oral evidence given on 2 May 2013 (paras 17 and 72-86), by a representative from the North Wales Citizen Panel for Social Services on 16 May 2013. The Record of Proceedings for these dates is available at National Assembly for Wales (undated) <<http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?Id=5664>> accessed 31 July 2019.

²⁶ Written responses to the Bill from Disability Wales, the Arfon Access Group, Age Cymru, Cymorth Cymru and the City and County of Swansea. All available at National Assembly for Wales, ‘Social

Committee, and the indications in the *Framework* that the forthcoming legislation would enable independent living, duties relating to independent living, the social model and the UNCRPD were all omitted from the Act; and a medical model definition of 'disability' was provided on the face of the statute.²⁷ In giving her reasons for not including or supporting provisions relating to independent living in the Act, the Deputy Minister of the Welsh Government stated:

I would say that [independent living] is a service model and what we are developing is the legal framework. So, the Bill provides for independence and I believe that that will cover people's rights to independent living and their rights to independence.²⁸

After consideration of witness evidence, the H&SC Committee recommended that independent living *should* be included in the definition of wellbeing provided in the statute, but also appeared to misunderstand its meaning. The Committee reproduced the comment of the Minister unchallenged²⁹ and suggested that:

... the existing definition of well-being should make reference to suitable housing and independent living.³⁰

The reason given by the Minister for preferring a medical, rather than a social model of disability in the legislation, despite the Welsh Government's own stated commitment to the social model,³¹ was that the social model is a 'concept' with no existing basis in law.³² The H&SC Committee agreed with this position and added:

Services and Well-being (Wales) Bill: Consultation responses' (undated)

<<http://www.senedd.assembly.wales/mglIssueHistoryHome.aspx?lId=5961>> accessed 21 July 2019.

²⁷ Section 3(5) incorporates the definition of disability found in the Equality Act 2010. Section 6(1) of the Equality Act 2010 states that a person has a disability if they have a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

²⁸ National Assembly for Wales, Record of Proceedings, 6 June 2013, Para 51.

²⁹ H&SC Committee (n8) para 69.

³⁰ *Ibid* page 50

³¹ See Chapter 2, section 3.

³² National Assembly for Wales, Record of Proceedings, 18 April 2013, para 91.

We believe there is a risk that clarity around access to care and support could be diluted as a result of using the social model of disability, which may not translate readily into service provision.³³

The Committee recommended that the Welsh Government should consider how the social model might be ‘embedded in practice’ through regulations and guidance.³⁴

In early written submissions, the Wales Alliance for Mental Health³⁵ lobbied for the UNCRPD – and the UNCRC – to be placed at the outset of the Act, as a means of indicating that the Act sat in the context of these UN Conventions.³⁶ This was considered by the H&SC Committee during its scrutiny of the Bill,³⁷ although there appeared to be some confusion as to which UN Convention was under discussion.³⁸ The final absence of any reference to the UNCRPD in the Act stood in stark contrast to the treatment of the UNCRC and the legally non-binding UN Principles for Older People – both of which *are* referenced on the face of the statute.³⁹ Ultimately, a statement requiring local authorities to have due regard to the UNCRPD was inserted into the final version of the Code of Practice on Part 2 of the Act,⁴⁰ although references to the Convention were omitted from other Codes, including those on safeguarding, which include references to the UNCRC, the UN Principles for Older Persons and the European Convention on Human Rights.

3.1. Independent living: Discussion

³³ H&SC Committee (n8) page 38.

³⁴ *Ibid.*

³⁵ The Wales Alliance for Mental Health is a network of third sector organisations that work in this area, including DPOs and non-DPOs.

³⁶ National Assembly for Wales, Record of Proceedings, 2 May 2013 para 86.

³⁷ *Ibid.*

³⁸ *Ibid.*, paras 72-89.

³⁹ Section 7(1) and 7(2). While the reason for the duty relating to the UNCRC was presumably the existing duty on the Welsh Government to have due regard to this Convention and its strong focus on the rights of children (see Chapter 8, Section 2.2), the incorporation of the Principles appears to have been the result of a voting error (see section 3.1, below).

⁴⁰ Welsh Government, ‘Social Services and Well-being (Wales) Act 2014: Part 2 Code of Practice (General Functions)’ (2015) para 67.

These matters demonstrated two core issues. Firstly, neither the importance nor – perhaps more critically – the *content* of independent living was understood by AMs or the Welsh Government. The opportunity to incorporate a right to independent living into domestic legislation in Wales was rejected not, apparently, on a matter of principle, but because AMs, including the Deputy Minister responsible for both the *Framework* and the Bill,⁴¹ continued to understand the phrase 'independent living' – and to reproduce it in a social care context – as some kind of 'service model', or a particular form of living arrangement connected to housing and possibly akin to supported living. There was also a clear conflation of independent living with the much broader concept of 'independence' (discussed fully in section 4, below). The social model, which underpins independent living, was equally poorly understood. The statements by the Minister and the Committee ignore the fact that Article 1 of the UNCRPD gives legal expression to the social model,⁴² and imply an ongoing understanding in the National Assembly for Wales ('the Assembly') of 'service provision' as an end in itself rather than the use of support as a means to effect barrier removal. It appeared that while the social model had been superficially accepted by the Welsh Government and the Assembly, a full understanding of the model, and commitment to implementing it remained tenuous.

Secondly, there was an ambivalent approach in both the Assembly and the Welsh Government to the UNCRPD. The inclusion of the UNCRC in the Act demonstrated both an awareness of international legislation and a willingness to incorporate this into domestic legislation if desired. The development of the *Framework* – almost contemporaneously with the Bill – indicated that the Welsh Government must also have been aware of their international obligations under the UNCRPD, although this

⁴¹ Chapter 9, section 1.

⁴² Article 1 states (in part) 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. In 2013, the Court of Justice of the European Union referenced Article 1, and stated: 'The concept of 'disability' in Council Directive 2000/78/EC of 27 November 2000 ... must be interpreted as including a condition caused by an illness medically diagnosed as curable or incurable where that illness entails a limitation which results in particular from physical, mental or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers, and the limitation is a long-term one'. *HK Danmark v Dansk almennyttigt Boligselskab* (C-335/11) [2013] 3 C.M.L.R. 21 (ruling 1). The EU has ratified the UNCRPD.

knowledge clearly remained hazy. The decision not to incorporate either the UNCRPD or independent living was therefore *intentional*, and a matter of disability policy. The reasons for this were not entirely clear. There was certainly relatively little focus by disability organisations on the UNCRPD in initial written responses to the Bill, when compared with the focus by certain child-focused agencies – particularly the Children’s Commissioner – on the UNCRC⁴³ – although this itself may have been a reflection of the pre-existing and strong focus on the UNCRC in the Assembly and Welsh Government. Another factor may have been the lack of a ‘champion’ for the UNCRPD within the Assembly. The UN Principles for Older People were included in the Act largely as a result of the lobbying activities of an AM who tabled amendments to this effect⁴⁴ – although it was also partially due to a voting error.⁴⁵ The Act suggested that while children’s rights have become a part of the legislative ‘landscape’ in Wales, the rights of working age disabled people and the ideas of the disabled people’s movement continue to have limited traction where social care is concerned.

4. Independence in the Act

While neither independent living nor the UNCRPD was incorporated into the Act, *independence* was placed on the face of the statute and cited as a key principle from the early stages of the legislative process. In her written statement on the introduction of the Bill, the Deputy Minister stated:

⁴³ Children’s Commissioner for Wales, ‘Health and Social Care Committee - Scrutiny of Social Services and Well-being (Wales) Bill: Response to consultation’ (15 March 2013) <<http://www.senedd.assembly.wales/documents/s15328/SSW%2058%20Childrens%20Commissioner%20for%20Wales.pdf>> accessed 31 July 2019.

⁴⁴ Darren Millar AM (Conservative) tabled an amendment at Stage 3 of the Bill which would create ‘a duty on Welsh Ministers, local authorities, NHS organisations and others to have due regard to the UN Principles for Older Persons when exercising their functions under the Bill’. National Assembly for Wales Record of Proceedings, 4 February 2014 at 15:13. At the report stage of the Bill, Darren Millar sought an amendment that would extend this requirement also to the UNCRC. National Assembly for Wales Record of Proceedings, 18 March 2014 at 16:32. The UNCRPD was not included in these discussions.

⁴⁵ Julie James AM intended to vote against the amendment introduced by Darren Millar, but abstained in error, by pressing the wrong button during the voting process. National Assembly for Wales, Record of Proceedings, 4 February 2014 at 16:39.

[The Bill] will transform the way social services are delivered, primarily through promoting people's independence to give them stronger voice and control.⁴⁶

Variations on this statement were included in the letter introducing the Consultation on the Social Services and Well-being (Wales) Bill⁴⁷ and in the Explanatory Memorandum to the Bill.⁴⁸ They were also uttered by members of the opposition⁴⁹ and were included in information on the Act on the Welsh Government website in the run up to the implementation of the Act in April 2016. Perhaps unsurprisingly, given this focus, in its passage through the Assembly, the Bill gained two provisions that require the promotion of the independence of those using, or potentially using, social care support. One of these forms part of the 'overarching duties' that supplement the well-being duty. It requires anyone carrying out functions under the Act in relation to an adult to have regard to:

the importance of promoting the adult's independence where possible.⁵⁰

Paragraphs inserted into the final guidance relate this provision to independent living, citing the UNCRPD – in particular Article 19 – and the *Framework*. The Code of Practice to Part 2 of the Act states (original emphasis):

Local authorities **must** have regard to the importance of promoting the adult's independence where possible. ... For a person who needs care and support and a carer who needs support it is intended that well-being includes key aspects of independent living, as expressed in the UN Convention on the Rights of Disabled People, in particular, Article 19 of the Convention. The

⁴⁶ Gwenda Thomas AM, 'Written statement by the Deputy Minister for Children and Social Services' (*Welsh Government*, 28 January 2013) <<http://gov.wales/about/cabinet/cabinetstatements/previous-administration/2013/introsocservbill/?lang=en>> accessed 7 June 2016.

⁴⁷ Mark Drakeford AM, Chair: Health and Social Care Committee, 'Consultation Letter' (1 February 2013) <<http://www.senedd.assembly.wales/documents/s13973/Consultation%20letter.pdf>> accessed 31 July 2019.

⁴⁸ Welsh Government, 'Social Services and Well-being (Wales) Bill: Explanatory Memorandum' (2013), 4.

⁴⁹ See, for example, the statement by William Graham, National Assembly for Wales, Record of Proceedings, 29 January 2013 at 14.56.

⁵⁰ Section 6(3)(b).

approach to promoting people's well-being by identifying the personal outcomes that they wish to achieve in all aspects of their everyday lives, and the barriers that they may face in achieving these outcomes... recognises that disabled people can achieve their potential and fully participate as members of society, consistent with the Welsh Government's Framework for Action on Independent Living. The Welsh Government's Action on Independent Living Framework (sic) expresses the rights of disabled people to participate fully in all aspects of life.⁵¹

This was the single reference to independent living as it was understood by the disabled people's movement in the guidance issued under the Act. It created a further conflation of independent living with the ambiguous principle of independence.

The second provision, in section 15, requires local authorities to:

provide or arrange for the provision of a range and level of services which it considers will ... [enable] people to live their lives as independently as possible.⁵²

Section 15 relates to services that will prevent needs from arising and includes a requirement that local authorities provide services that – in wording that deviates from social model principles – they consider will '[minimise] the effect on disabled people of their disabilities'.⁵³

The Record of Proceedings indicates that in the debate around these provisions, the concept of independence was understood by AMs to encompass all its meanings, including self-reliance *and* self-determination, without particular separation.⁵⁴ This

⁵¹ Welsh Government, 'Code of Practice Part 2' (n40) paras 55-58.

⁵² Section 15(2)(i).

⁵³ Section 15(2)(d). Note that this relies on the medical model of disability, despite the Welsh Government's commitment to the social model.

⁵⁴ Kirsty Williams AM, for example, moved an amendment in which independence was connected primarily with the notion of autonomy, but also spoke of independence in terms of the ability to do things for oneself. The fluid use of the idea of independence is seen particularly in the stage 2 debate on certain amendments. See, for example, National Assembly for Wales, Record of Proceedings, 13

was echoed in the guidance. When references to independence in the Codes of Practice were examined, they were relatively evenly split between references to independence as self-reliance, as self-determination, or used ambiguously.

There was, however, a strong focus in the guidance on not using, or minimising the use of, social care support, which was often expressed through the idea of independence in the form of self-reliance. This was particularly seen in the passages relating to the section 15 duty, and the eligibility criteria. The guidance on the section 15 duty focused largely on the regaining of functional ability, with the aim of reducing a need for services and thus improving their sustainability. Similarly, the case studies on eligibility held a tacit value of not needing social care support, with independence-as-self-reliance set out as an assumed benefit to the individual.⁵⁵ Elsewhere in the guidance the use of services was even expressed as a negative form of dependency:

An evaluation of risk is essential to determining a need for care and support. Here the analysis of risk is *based on* an understanding of those risks which will prevent people becoming too dependent on services and undermine their potential for meeting their personal outcomes (emphasis added).⁵⁶

In this paragraph the use of social care services is equated with a dependency that *prevents* a person's from living a life of their meeting their personal outcomes. It runs directly counter to the idea within independent living that assistance in day-to-day life

November 2013, particularly the contributions by Kirsty Williams AM, William Graham AM and the deputy Minister Gwenda Thomas AM.

⁵⁵ The first case study, for example, reads (in full): Mr. Evans, a 45 year old man with learning disabilities who has been living with an elderly parent who has perhaps been over protective and done everything for him may need some form of reablement programme to help him move to new accommodation and take more responsibility for looking after himself. He is unable to carry out basic personal care activities and may need help to develop social networks. He will have short term intensive eligible needs where he has become very dependent but has the potential to develop skills to make him more independent. He will receive community based services alongside managed services delivered through a care and support plan. Productive social work and wellbeing services should, over time, support Mr. Evans to develop such independence skills that his needs no longer become eligible and he is either fully independent or is supported solely by community based services.

⁵⁶ Welsh Government, 'Social Services and Well-being (Wales) Act 2014: Part 3 Code of Practice (Assessing the Needs of Individuals)' (2015), page 27. This is a section that focuses on establishing personal outcomes in the assessment process. The word 'prevent' makes little sense in this context and it is presumed that the wording is a result of revision while the draft was in progress.

is a positive force that *supports* independence in the sense of individuals living the life of their choice.

This emphasis on minimising the need for services was also contained in various explanatory memoranda to the Regulations under the Act, in which independence is introduced as a means of controlling demand. The memoranda carry a strong focus on the sustainability of social care, explaining that while demands on social services are increasing in Wales, available budgets have decreased. Independence is established as a central tool in the management of this difficulty. The explanatory memoranda to the Regulations on both assessment⁵⁷ and eligibility criteria⁵⁸ each state (with minor variations):

Due to this increase in demand it is essential that the future delivery of social care is transformed as the current system is unsustainable.... The primary objective of the policy is to promote an individuals' (sic) independence and ensure they have a stronger voice and control over their care and support services.⁵⁹

While independence here is connected with aspects of self-determination, the *intention* relates to a reduction in support. The memorandum on the Regulations on eligibility criteria goes on to state that the objective of the criteria is to:

reduce the number of people who require a care and support plan by introducing opportunities to help people retain independence, and access early intervention and prevention services without the need for a formal [care] plan.⁶⁰

⁵⁷ Welsh Government, 'Explanatory Memorandum to the Care and Support (Assessment) (Wales) Regulations 2015' (6 May 2015) <<http://www.assembly.wales/laid%20documents/sub-ld10199-em/sub-ld10199-em.pdf>> accessed 31 July 2019.

⁵⁸ Welsh Government, 'Explanatory Memorandum to the Care and Support (Eligibility) (Wales) Regulations 2015' (6 May 2015) <<http://www.assembly.wales/laid%20documents/sub-ld10198-em/sub-ld10198-em.pdf>> accessed 31 July 2019.

⁵⁹ *Ibid* 5-6.

⁶⁰ *Ibid* 6-7. 'Independence' in this section is stated to be connected to 'a person's voice and control over support', although the intended impact is more obviously connected to a lack of a need for state services.

The Regulations on eligibility criteria achieve this reduction by establishing that social care support will be provided *only* if a need cannot be met through informal support or ‘services in the community to which the adult has access’. This was originally referred to by the Welsh Government as ‘the can and can only test’ – that is, that social care support would be provided if it was capable of meeting the assessed needs and the *only* way of doing so.⁶¹ The eligibility criteria therefore write into law that informal, generic and charitable services – the very forms of support that, along with institutionalism, disabled activists had emphatically rejected – are now, in Wales, the *first* resort for individuals requiring assistance.⁶² There remains no unequivocal statement in the guidance that disabled people must not be required to obtain support from informal or generic services that they do not wish to use.

This reduction of provision has been presented by the Welsh Government as principle. In the early days of the Act, the Welsh Government indicated that the role of social care was to do the ‘minimum necessary’.⁶³ Both this minimisation of support

⁶¹ The first draft of the Code of Practice to Part 4 stated: ‘The person has needs which meet the eligibility criteria if an assessment establishes that they can, and can only, overcome barriers to achieving their well-being outcomes by the local authority preparing a care and support plan (or a support plan for a carer) to meet their assessed needs, and ensuring that the plan is delivered. This principle has come to be known as ‘The Can and Can Only Test’ The first part of the Can and Can Only Test is whether or not a care and support intervention can address the need, risk or barrier, or enhance the resources that will enable the individual to achieve their personal well-being outcomes. ...The second part of the test is the determination that the individual’s well-being outcomes cannot be met, or cannot be sufficiently met, solely through care and support co-ordinated by themselves, their family or carer, or others, and so the individual requires support to co-ordinate that care and support or to manage it completely.’ Welsh Government, ‘Part 4 – Code of Practice on the Exercise of Social Services Functions in Relation to Part 4 (Meeting Needs) of the Social Service and Well-being (Wales) Act 2014 (Draft)’ (undated but downloaded in December 2014), Page 8.

⁶² Clements describes the early expression of this system as a ‘retrenchment: from individually tailored packages to a standard fixed menu of take it or leave it services; services that have to be tried and proven to fail before the person can become eligible. In this Orwellian scheme “preventive services” mean services that prevent access to personalised support.’ Luke Clements, ‘Welsh Social Care Law Risks Taking Us Back 20 Years by Providing Bare Minimum’ (*Community Care*, 2 January 2015) <<https://www.communitycare.co.uk/2015/01/02/welsh-social-care-law-risks-taking-us-back-20-years-providing-bare-minimum/>> accessed 31 July 2019.

⁶³ In November 2014, Mark Drakeford (then Minister for Health and Social Care) reportedly stated: that ‘minimum necessary’ intervention principle is a very important one in the Act – it’s the way we think that we will be able to deal with providing services... Extract of the text of an address by Drakeford to the Care Council for Wales, 21 November 2014, provided to the author by e-mail. E-mail from Luke Clements to author (and others), 7 December 2014. The link provided in that e-mail to the address is now deactivated. This principle is echoed in the Welsh Government’s concept of ‘prudent healthcare’, which underpins the NHS in Wales. This contains a central principle that health services should: ‘carry out the minimum appropriate intervention’. Mark Drakeford (then Minister for Health and Social Services), ‘Written Statement - Delivering Prudent Healthcare in Wales (Welsh Government, 11 July 2014) <<https://gov.wales/about/cabinet/cabinetstatements/previous->

and the use of the idea of independence in achieving this were in contradiction with the Welsh Government's own formerly-stated principles. It is stated in Chapter 9 that the Welsh Government had explicitly *rejected* independence as a principle for social care policy in the white paper, on the basis of its isolationist connotations.⁶⁴ The white paper had also emphatically rejected reductions in social care support. It stated:

There is a choice: retrenchment or renewal. Retrenchment would see fewer people receiving services, greater expectations that people find their own solutions, increased burdens on informal carers These are not options that will meet the needs of the people of Wales.⁶⁵

In the context of austerity, however, and faced with the fact of creating legally actionable entitlements, the Welsh Government's own principles were entirely overwhelmed. Following objections, the language of both the can and can only test and doing the minimum necessary were dropped. In practice, however, the test remains,⁶⁶ and veiled references to doing the minimum necessary can still be found.⁶⁷

administration/2014/prudenthealthcare/?lang=en> accessed 21 December 2018. The other principles are: do no harm; organise the workforce around the "only do, what only you can do" principle; promote equity; and remodel the relationship between user and provider on the basis of co-production.

⁶⁴ Section 3. As a reminder, the white paper stated: 'We look not for independence and separateness, but for interdependency with those around us' Welsh Assembly Government, (n10) para 2.2.

⁶⁵ Ibid para 1.11.

⁶⁶ The test remains effective in the Regulations and references to the 'can and can only test' can be found in Assembly documents despite the relinquishing of this term. See, National Assembly for Wales Research Service, 'Key Issues for the Fifth Assembly' (*NAW Research Service* 2016) <<http://www.assembly.wales/research%20documents/key%20issues%20-%20english/key%20issues%20-%20english-linked.pdf>> accessed 20 September 2017, 42.

⁶⁷ For example: 'The new Social Services and Well-being Act will transform social care in Wales... People will become more empowered partners in both assessing and meeting their needs, with the expectation that there will be reduced reliance on state support. ...Even when a professional assessment is necessary, the aim will be to provide care and support at the lowest level, so that risk is managed in partnership with people and their family or networks and independence is maximised.' Sue Evans (Chief Officer, Social Care and Housing, Torfaen County Borough Council), 'Delivering Excellence Across the Health and Social Care System through Prudent Healthcare' (*Making Prudent Healthcare Happen*, undated) <<http://www.prudenthealthcare.org.uk/socialcare/>> accessed 21 December 2018. The Welsh Government's webpage on the 2014 Act states, '[the Act] promotes a range of help available within the community to reduce the need for formal, planned support'. Welsh Government, 'Care and Support in Wales is Changing' (Welsh Government, 24 August 2017) <<https://gweddill.gov.wales/topics/health/socialcare/act/?lang=en>> accessed 1 August 2019.

4.1 Independence: Discussion

The connection of independent living to the language of independence, and the need for the disabled people's movement to create a counter-narrative to master narratives of independence – described as a feat of 'linguistic reclamation – is discussed in Chapter 8. It is suggested there that independence would become a site of ambiguity and struggle when the counter-narrative of independent living was inserted into policy.

The use of the concept of independence demonstrated that independent living remained – as discussed above – deeply unfamiliar to policy makers in Wales, with the distinction between different elements of independence unstated and unrecognised. Essentially, the risk taken by the disabled people's movement in using the language of independence had eventuated, with three difficulties emerging. Firstly, independence was used to express multiple ideas without distinction or separation, demonstrating the profound linguistic and conceptual difficulty in separating these ideas that is discussed in Chapter 8.⁶⁸ It was clear that AMs understood the ability to do things for oneself – a central aspect of self-reliance – as an element of autonomy and self-determination and, to some extent, used the ideas interchangeably. Secondly, and partially as a result, the power of the master narrative of independence as self-reliance nudged the content towards those ideas that disabled activists had strenuously sought to reject, indicating that the struggle for meaning was being lost. In doing so, independent living – explicitly connected to independence under section 6 of the Act – had the potential also to be further misunderstood, pulled into this narrative and distorted in the process.

Finally, in the climate of austerity this rejected master narrative of independence came to the fore as an intentional means of resource management. Not only was

⁶⁸ Section 3.2.

the attempt at linguistic reclamation – and the challenge of creating a counter-narrative of independence – in difficulty, but this unwanted master narrative of independence emerged as a ‘hidden’ master narrative of the legislation, competing with – or even displacing – wellbeing as the central purpose of the Act. Here the Welsh Government relied on the fact that independence – regardless of its meaning or construction – is almost invariably viewed as, or assumed to be, a positive outcome.⁶⁹ It ignored the fact that when self-reliance is conceptualised as the only, or primary, outcome for disabled people it can be damaging. In this context, the value that the disabled people’s movement had obtained in deploying an idea which holds universal appeal and which demonstrated commonality between disabled and non-disabled people was entirely negated.

5. The wellbeing duty and other ‘overarching duties’

The incorporation of wellbeing as a central principle for a social care statute was recommended by the Law Commission.⁷⁰ As discussed above, various organisations, including DPOs, advocated for the enjoyment of the right to independent living to be inserted into this duty. Indeed, the Commission itself had considered independent living as a potential underpinning principle, but rejected it, largely on the basis that it was ‘too imprecise’.⁷¹ Whether the Commission *understood* independent living is debateable – it appeared to equate independent living with living alone or supported living arrangements and argued that in certain circumstances it ‘could clash with the choice and control principle’.⁷² The Law Commission did not set out any suggested definition of wellbeing, although it discussed the inclusion of various possible elements, some of which were already present in Westminster and Welsh policy, including choice and control.⁷³

⁶⁹ See chapter 8, section 3.

⁷⁰ Law Commission, *Adult Social Care* (Law Com No 326, 2011).

⁷¹ *Ibid* para 4.35. The Law Commission also considered that independent living was adequately covered by the UNCRPD (para 4.36). It acknowledged that a ‘small majority of consultees who expressed a view’ had argued for independent living to be included in the statute (para 4.9).

⁷² *Ibid* para 4.9.

⁷³ *Ibid*, Part 4. These ideas were already firmly rooted in Westminster social care policy, and their consideration by the Law Commission represented an acknowledgement of this policy as much as interest in the concept of independent living.

In Wales, the importance of wellbeing was elevated by its incorporation into the final title of the Act.⁷⁴ It therefore acts as a broad encompassing form of ‘common sense’ for the statute. Whether it goes so far as to comprise a master narrative of the Act is questionable – its particular elasticity of meaning (discussed in Chapter 8, Section 2.2) means that wellbeing as yet lacks a dominant meaning or ‘story’ in the policy context in the way that ‘self-reliance’ acts as a master narrative of independence. It does, however, create a broad standard against which outcomes must be measured.

The well-being duty forms the first substantive section of the Act, and underpins every provision of the statute. Section 5 states:

Well-being duty

A person exercising functions under this Act must seek to promote the well-being of -

(a) people who need care and support,⁷⁵

The definition of well-being is contained in section 2 of the Act and states:

2 Meaning of “well-being”

(2) “Well-being”, in relation to a person, means well-being in relation to any of the following -

(a) physical and mental health and emotional well-being;

(b) protection from abuse and neglect;

(c) education, training and recreation;

(d) domestic, family and personal relationships;

(e) contribution made to society;

(f) securing rights and entitlements;

(g) social and economic well-being;

⁷⁴ The original proposed title of the statute was the Social Services (Wales) Bill. See, Welsh Government, ‘Consultation Document: Social Services (Wales) Bill’ (2012) <<http://gov.wales/docs/dhss/consultation/120312consultationen.pdf>> accessed 23 February 2018.

⁷⁵ Section 5(b) extends this duty to ‘carers who need support’. Throughout the Act, carers are included in the general provisions and under the same structures that apply to ‘people who need care and support’. For reasons of space, sections relating to carers are omitted from this thesis.

(h) suitability of living accommodation.

....

(4) In relation to an adult, “well-being” also includes -

(a) control over day to day life;

(b) participation in work.

The relevant Code of Practice sets out a series of ‘national well-being outcome statements’ under each of these statutory aspects of wellbeing. These augment the definition of well-being and are said to form part of it.⁷⁶ During the assessment process for social care support, a series of ‘personal outcomes’ must be established, each of which must relate to one of these national outcomes.⁷⁷ This legal focus on personal outcomes is a distinctive feature of the Act, and is one of the key means by which the individuality of people using social care support is acknowledged and their personal and social agency potentially enabled. Such individual ‘wellbeing outcomes’ have been connected to independent living where wellbeing has been discussed by the Welsh Government.⁷⁸ The national outcomes are written in the first person and read:

What well-being means	National well-being outcomes
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⁷⁶ Welsh Government, ‘Code of Practice Part 2’ (n40) 9-10. The Welsh Government is obliged to issue a statement of wellbeing outcomes under section 8(1) of the Act. The statement was issued in August 2016, and is available at Welsh Government, ‘Well-being Statement for People Who Need Care and Support and Carers Who Need Support (2016) <<https://gov.wales/docs/dhss/publications/160831well-being-statementen.pdf>> accessed 31 July 2019.

⁷⁷ Welsh Government, ‘Code of Practice Part 3’ (n56).

⁷⁸ In a statement on the closure of the Welsh Independent Living Grant, the then Minister for Children, Older People and Social Care stated, ‘The Welsh Government is committed to independent living so that disabled people, wherever they live in Wales, are appropriately supported to achieve their wellbeing outcomes within their communities. As a result the majority of disabled people are supported to do this by their local authority who, under our social services legislation, have a legal duty to help them achieve their wellbeing outcomes. This will include their desire to live as independently as possible’ and ‘I am writing to local authorities to reinforce the importance of this transition and of the conversations they are holding with people in ensuring they receive the future support particular to them to deliver their wellbeing outcome of living independently in the community’. Huw-Irranca Davies, ‘Written Statement - Welsh Independent Living Grant – Update’ (*Welsh Government*, 23 May 2018) <<https://gov.wales/about/cabinet/cabinetstatements/2018/welshilgupdate/?lang=en>> accessed 12 July 2018.

Securing rights and entitlements Also for adults: Control over day-to-day life	I know and understand what care, support and opportunities are available and use these to help me achieve my well-being I can access the right information, when I need it, in the way I want it and use this to manage and improve my well-being I am treated with dignity and respect and treat others the same My voice is heard and listened to My individual circumstances are considered I speak for myself and contribute to the decisions that affect my life, or have someone who can do it for me
Physical and mental health and emotional well-being Also for children: Physical, intellectual, emotional, social and behavioural development	I am healthy and active and do things to keep myself healthy I am happy and do the things that make me happy I get the right care and support, as early as possible
Protection from abuse and neglect	I am safe and protected from abuse and neglect I am supported to protect the people that matter to me from abuse and neglect I am informed about how to make my concerns known
Education, training and recreation	I can learn and develop to my full potential I do the things that matter to me
Domestic, family and personal relationships	I belong I contribute to and enjoy safe and healthy relationships
Contribution made to society	I engage and make a contribution to my community I feel valued in society
Social and economic well-being Also for adults: Participation in work	I contribute towards my social life and can be with the people that I choose I do not live in poverty I am supported to work I get the help I need to grow up and be independent I get care and support through the Welsh language if I want it
Suitability of living accommodation	I live in a home that best supports me to achieve my well-being

The wellbeing duty is supplemented by a number of 'other overarching duties' in section 6. The relevant parts of the section read:

(6)(2) A person exercising functions under this Act... must —

(a) in so far as is reasonably practicable, ascertain and have regard to the individual's views, wishes and feelings,

(b) have regard to the importance of promoting and respecting the dignity of the individual,

(c) have regard to the characteristics, culture and beliefs of the individual (including, for example, language), and

(d) have regard to the importance of providing appropriate support to enable the individual to participate in decisions that affect him or her to the extent that is appropriate in the circumstances, particularly where the individual's ability to communicate is limited for any reason.

(3) A person exercising functions under this Act in relation to an adult ... must, in addition, have regard to —

(a) the importance of beginning with the presumption that the adult is best placed to judge the adult's well-being, and

(b) the importance of promoting the adult's independence where possible.

5.1. The wellbeing duty: Discussion

It is stated above that, as the underpinning principle of the Act, the wellbeing duty forms the context in which independent living must be realised if the Act is to be effective in enabling it as an outcome of social care provision. As has already been shown, the Act – and therefore the wellbeing duty – was crafted without a full or accurate understanding of independent living on the part of the Welsh Government or AMs, and attempts by DPOs to lever independent living into the content of wellbeing were unsuccessful. The wellbeing duty was therefore not devised as an attempt to realise independent living in law. It was also required to be applicable to *all* groups receiving support under the Act and to the needs of people as diverse as older people with age related conditions such as dementia, highly activist working age disabled people, and looked-after children whose needs stem from family circumstances rather than any form of impairment. It was therefore necessary for the principle to encompass a very broad range of needs and priorities.

It is worth noting at the outset that, legally speaking, the wellbeing duty and the other overarching duties are weak. Section 5 is a general duty which confers no legally enforceable rights on individuals, and its broad wording raises questions as to its enforceability and usefulness.⁷⁹ Similarly, the obligation to ‘have regard’ to the various elements indicated in section 6 does not require a person to prioritise or give particular weight to that matter, and does not preclude a decision maker from taking other relevant matters into account, including those not listed in the legislation or guidance, such as resources. This is emphasised in the guidance.⁸⁰

The wellbeing duty demonstrated, above all, the difficulty on the part of policy makers in Wales in understanding the importance of, and embracing, a shift in narratives around those using social care that was also seen in the sections of the *Framework* in which social care was discussed.⁸¹ While certain fragments of the independent living counter-narrative were referenced, they were undermined by a lack of conviction as to their content, by a reversion to the Welsh Government’s own principles or a disinclination to embrace colliding ideas, and – almost certainly – by a fear of creating entitlements in the austerity context.

Perhaps the most notable aspect of the duty is the lack of personal agency – the element of independent living that collided most forcefully with the Welsh Government’s communitarian narrative. While many aspects of social agency are directly referenced in the definition of wellbeing provided on the face of the Act,

⁷⁹ In relation to the equivalent duty in the Care Act 2014, Clements suggests that ‘there is a risk that it may prove to be of little practical application’. Luke Clements, ‘The Care Act 2014 Overview’ (updated 3 November 2017) <<http://www.lukeclements.co.uk/wp-content/uploads/2017/11/Care-Act-notes-updated-2017-08.pdf>> accessed 31 July 2019, 5. However, the High Court has held that an assessment of needs must assess the impact of a person’s need for care and support on the various factors of wellbeing and must assess the outcomes that the person wishes to achieve in their day-to-day life. **R (JF) v The London Borough of Merton** [2017] EWHC 1519 (Admin). For an analysis of this case see Luke Clements, ‘R (JF) v Merton LBC ~ High Court Social Care Law Assessment Judgment’ (17 July 2017) <<http://www.lukeclements.co.uk/r-jf-v-merton-lbc-high-court-social-care-law-assessment-judgment/#http://www.bailii.org/ew/cases/EWHC/Admin/2017/1519.html>> accessed 31 July 2019.

⁸⁰ The guidance states that this is, ‘is similar to a requirement to ‘consider’ or ‘take into account’ that matter, and that, ‘A local authority should give the weight that is appropriate in all the circumstances, balancing this against any other countervailing factors that are relevant to the decision in question.’ Welsh Government, ‘Code of Practice Part 2’ (n40) paras 59-61.

⁸¹ See Chapter 10.

personal agency is weak. 'Control over day to day life' is included in the definition, but the connected wellbeing outcomes are highly limited. For those using social care support, one's voice 'is heard and listened to' rather than one's choices enabled and respected, and 'individual circumstances are considered' rather than acted upon. Control over one's *support* is notably absent, and choice appears only in the wellbeing outcomes where the Welsh Government's own principle of 'voice' is also present.

Choice was incorporated into the supporting overarching duties, but remains compromised. The conditional presumption in section 6(3)(a) that 'the adult is best placed to judge [their own] well-being', establishes well-being as a *subjective* matter and gives a certain scope for individuals to lay claim to the interpretation of well-being that is relevant to them, and to argue for support that enables it.⁸² Against the recommendation of the Law Commission, the provision relates to *all* individuals including those who, under other legislation, may be deemed to lack the capacity to make the decision in question.⁸³ The presumption is, however, undermined by the provision in 6(2)(a), which is an expression of individual choice that falls significantly short of the recommendation made by the Law Commission. The Commission recommended that the statute should state that:

... decision makers must... *follow* the individual's views, wishes and feelings wherever practicable and appropriate...(emphasis added).⁸⁴

In the Act, the concept of individual choice – which explicitly collides with the Welsh Government communitarian narrative – is therefore notably and *intentionally* weakly phrased.

⁸² Clements notes that this provision 'creates a default position...for which a local authority will have to produce evidence if it wishes to rebut' Luke Clements, 'Social Services & Well-being (Wales) Act 2014: An Overview' (updated May 2019) <<http://www.lukeclements.co.uk/wp-content/uploads/2019/05/Wales-SS-Well-being-Act-31.pdf>> accessed 1 August 2019, 4.

⁸³ The Law Commission recommended that such a provision should be included, but restricted it to people considered under legislation to have the capacity to make the relevant decision. Law Commission (n70) para 5(2)(a).

⁸⁴ *Ibid* para 5(2)(b).

This lack of personal agency was emphasised by the phrasing of the national wellbeing outcomes in the first person. It is presumed that this phraseology was selected to place the individual at the centre of the wellbeing provision. It has the additional impact, however, of creating an element of coercion, particularly in relation to behavioural aspects. The voice of the individual is imposed, rather than consensual, and matters presented as personal choice are in fact obligations. The individual is expected, not choosing, to 'manage and improve my wellbeing', to treat people with 'dignity and respect', and to 'do things to keep myself healthy'. Passivity is deeply rooted. Under the statements that apparently construct a level of personal and social agency there is an individual who is non-empowered and obligated, suggesting a perpetuation of the 'traditional' identities for disabled people that emerged from narratives of deficit, otherness and 'care'.

Of all the elements of independent living those of equality and rights were least visible in the wellbeing duty. For these fragments, adjacency was not enough to ensure integration into policy and law. The reference to 'securing rights and entitlements' potentially signals a connection with human rights or the broad entitlements of citizenship, but the matters discussed in the wellbeing outcomes pertain solely to legal entitlements relating to social care. Most notably absent is any sense of equality between disabled and non-disabled people. These omissions may have been partly due to the austerity context – there is no doubt that the effective implementation of rights and the achievement of full and effective equality between disabled and non-disabled people requires resources. It also appeared, however, that equality and the rights of citizenship had somehow been 'misplaced', as if non-relevant to those using social care. The lack of any explicit references to equality combined with the hesitant approach to personal agency suggested – as did the *Framework* – that the Welsh Government was still struggling to envisage full and equal life and citizenship outcomes for those using social care, and to shift towards, or develop, new forms of identity and agency for this group.

Where the wellbeing duty, and particularly the wellbeing outcomes, apparently came into their own, so far as independent living was concerned, was in relation to the ideas of community and inclusion. The statements demonstrated a clear interest in these ideas, with references to 'my community', and being 'valued in society'. The

strongest of these – ‘I belong’ – is a clear statement of social membership, albeit with overtones of ownership. Community and inclusion are among the fragments of independent living that are ‘adjacent’ to elements of the Welsh Government communitarian narrative. These statements, and the legal requirement to connect an individual’s *personal* outcomes to a set of *national* wellbeing outcomes are expressions of the Welsh Government’s interest in these concepts. Here, however, they demonstrate that this adjacency is as problematic as it might be valuable. The connection of personal to national outcomes creates objectives and ambitions that are *purportedly* those of the individual but are jointly ‘owned’ by the individual and the broader public, establishing a connection between the individual and the communal that is imposed rather than selected. A similar outcome is seen in the eligibility criteria discussed briefly above. These also adhere to the Welsh Government’s focus on universalism in services – albeit for reasons of austerity rather than principle – but result in a form of enforced communitarianism to which individual personal agency is subject. This is directly contradictory to the form of sought community membership and engagement, conducted on the individual’s own terms, that is established in independent living.

6. Direct payments in the Act

It has already been established in this thesis that direct payments were introduced to Wales through social care legislation that it inherited from Westminster and that the individualism that they both demonstrated and enabled collided with core principles of the Welsh Government communitarian narrative. The disabled people’s movement in Wales demonstrated various ways in which collective uses of direct payments, might overcome the difficulties posed by this collision – particularly through the then developing idea of citizen-directed support (CDS). In the Welsh Government policy documents direct payments were positioned as a central mechanism of social care support and connected to the fragments of independent living that made up the narrative of personal agency, but were also simultaneously ‘neutralised’ in that they were disconnected from the support mechanism of personal assistance and connected instead to ‘services’ and did not result in the *realisation* of personal or

social agency. Ultimately, direct payments operated in the documents as a form of narrative ‘container’ in which elements of independent living that collided with principles of the Welsh Government communitarian narrative, particularly those of personal agency, were collected. In this context, the legal construction of direct payments becomes fundamental in upholding and enabling the counter-narrative of independent living.

Under the Act, direct payments hold a peculiar position. During the passage of the Bill, certain DPOs – including Disability Wales and Dewis CIL – argued that direct payments should be extended, with Disability Wales suggesting that they should become the default means of social care provision.⁸⁵ This was not enacted,⁸⁶ but the legislation relaxes restrictions on direct payment use.⁸⁷ The explanatory memorandum to the relevant Regulations⁸⁸ indicates the importance of direct payments both to the delivery of social care and the enabling of personal agency.

Direct payments are crucial They provide the mechanism to increase independence, choice and control, and are an enabler of co-production in care planning which affords individuals the freedom to plan flexible and innovative ways to maximise their well-being outcomes.⁸⁹

⁸⁵ See responses to the Bill from Disability Wales on behalf of Partner Organisations and Dewis CIL. Both available at National Assembly for Wales, ‘Social Services and Well-being (Wales) Bill: Consultation responses’ (undated)

<<http://www.senedd.assembly.wales/mglIssueHistoryHome.aspx?lId=5961>> accessed 21 July 2019.

⁸⁶ The H&SC Committee, as well as the Welsh Government, felt this would not be appropriate for many groups of people using the Act, particularly older people, partly because the evidence it received from service users was negative about direct payments. The Committee recommended that local authorities should be required to promote direct payments. H&SC Committee (n8)102.

⁸⁷ The regulations place no restrictions on the uses to which direct payments can be put. As a result the use of direct payments is relaxed and extended. Direct payments can now be used to purchase residential as well as domiciliary support, and support from the person’s local authority. The regulations also relax the restrictions on individuals using direct payments to purchase care from family members living in the same household; and remove the prohibition on the provision of direct payments to individuals with drug or alcohol dependency.

⁸⁸ The Care and Support (Direct Payments) (Wales) Regulations 2015.

⁸⁹ Welsh Government, ‘Explanatory Memorandum to the Care and Support (Direct Payments) (Wales) Regulations 2015 (21 October 2015) <<http://senedd.cynulliad.cymru/documents/s45952/CLA605%20-%20EM%20Rheoliadau%20Gofal%20a%20Chymorth%20Taliadau%20Uniongyrchol%20Cymru%202015%20Saesneg%20yn%20unig.pdf>> accessed 1 August 2019, pages unnumbered. The Memorandum goes on to say: ‘Direct payments must be seen as an integral part of the assessment and care planning process; they should no longer be viewed as a secondary consideration but as an important means, where appropriate, to meet a person’s need for care and support’.

Direct payments are also the only form of provision that are dwelt upon in any detail in the guidance.⁹⁰ As in the earlier Welsh Government policy documents, they are specifically connected to ‘choice, voice and control’,⁹¹ and there are various, sometimes strong, calls for direct payments to be used flexibly and innovatively. For example:

A local authority **must** be innovative and creative when working in partnership with recipients or their representatives to explore ways a direct payment can be used to secure the personal outcomes (original emphasis).⁹²

Despite such statements, direct payments also remain peripheral to the provision of support in the legislation. The Act provides nine examples of how needs may be met, of which direct payments are listed seventh,⁹³ and there is no mention of direct payments in any of the case studies on eligibility provided in the guidance. In these, needs are met through items including community-based services, ‘care and support services’, ‘emotional support’, specialist equipment, ‘one-to-one support from a specialist support worker’, and reablement services. Certain of these might be bought with direct payments, but this is not stated and no examples are provided.⁹⁴ No mention is made to personal assistance in the guidance, although there are brief references to direct payment recipients as employers. In addition, the decision was

⁹⁰ Roughly a quarter of the Code of Practice for Meeting Needs is devoted to direct payments. Other things covered in this Code are general background and context, eligibility, the preparation and format of care plans, ‘common considerations’ for care and support planning (that is, a set of general principles that should underlie decisions), the portability of care and support and case studies on eligibility. Welsh Government, ‘Social Services and Well-being (Wales) Act 2014: Part 4 Code of Practice (Meeting Needs)’ (2015).

⁹¹ Ibid para 128.

⁹² Ibid para 151. Among other things, the guidance also states that people using direct payments must be able to adjust the amount they use from week to week and bank unused money for occasions when future needs arise. This statement continues: ‘As long as overall the payment is being used to achieve the recipient’s personal outcomes, the actual weekly pattern of care and support does not need to be predetermined’. Para 159.

⁹³ Section 34(2) states: The following are examples of what may be provided or arranged to meet needs... (a) accommodation in a care home, children’s home or premises of some other type; (b) care and support at home or in the community; (c) services, goods and facilities; (d) information and advice; (e) counselling and advocacy; (f) social work; (g) payments (including direct payments); (h) aids and adaptations; (i) occupational therapy. Direct payments were inserted to this list as amendments introduced at Stage 2 of the legislative process, introduced by Kirsty Williams (Liberal Democrat) and William Graham (Conservative).

⁹⁴ Overall, the guidance is less comprehensive than that issued by the Welsh Government in 2004 and 2011 which, in both cases, was largely ‘imported’ from Westminster. See Chapter 9.

taken not to extend direct payments to health care provision,⁹⁵ despite a recommendation from the H&SC Committee that this should be done where people were in receipt of joint health and social care packages'.⁹⁶

Another absence in the Act or the guidance was any reference to CDS, despite statements in the *Framework* that this would be developed under the Act.⁹⁷ There were, however, new requirements that direct payments must serve communities as well as individuals, and that cooperative systems of direct payment use must be supported. The guidance states:

In addition to working with individuals to develop ways in which they can meet their requirements, a local authority **must** develop its direct payment scheme to be responsive to solutions and outcomes, and more relevant to the communities they serve. A local authority **must** work in partnership with local care and support providers to support initiatives which will meet well-being outcomes not only in the traditional way but through the development of citizen led direct payment co-operatives and social enterprises.⁹⁸

Elsewhere in the guidance, direct payments were also linked to the new duty on local authorities, under section 16 of the Act, to promote both the development of social enterprises, cooperatives and third sector organisations in the social care field, and the involvement of individuals and groups in the design and management of support – or co-production.⁹⁹ This 'section 16 duty' is unique to Wales and arises directly from the Welsh Government communitarian narrative. In the guidance it is pinned to the realisation of personal outcomes.¹⁰⁰

⁹⁵ The Code of Practice notes that local authorities are not permitted to provide healthcare and that this restriction extends to direct payments. Welsh Government, 'Code of Practice Part 4' (n90) para 133.

⁹⁶ H&SC Committee (n8) 102.

⁹⁷ Welsh Government, 'Framework for Action on Independent Living' (2013) 21 and 45.

⁹⁸ Welsh Government, 'Code of Practice Part 4' (n90) para 143.

⁹⁹ Welsh Government, 'Code of Practice Part 2' (n40) para 292.

¹⁰⁰ Ibid paras 207, 226 and 228.

6.1. Direct payments: Discussion

The ambivalence of the Welsh Government to direct payments was not resolved in the Act. As in the policy documents, support for direct payments was signalled, but there were also indications that they remained somewhat ‘alien’ to the Welsh Government’s approach to social care. It appeared that while the Welsh Government had assented to its inheritance, it remained antipathetic towards this mechanism that has been connected, in the Westminster context, with the marketisation of public services; and was more naturally comfortable with ‘traditional’ service provision that more readily enabled universalist and communitarian approaches. A non-questioning preservation of ‘traditional’ services, however, risked the perpetuation of their underlying narratives of otherness and deficit that independent living was designed to counter.

However, the connection of direct payments to the community, and to collective approaches to support provision indicated potential for new ideas to emerge. It is stated earlier in this thesis that the confluence of certain fragments of independent living and Westminster political narratives may have enabled a particular format of independent living to arise in England, and that the Welsh context might provide a testing ground for different approaches to be explored. Direct payments carry the potential for the individualism inherent in independent living to be ‘married’ with the communitarianism that forms a core principle of the Welsh Government narrative, particularly when connected with the section 16 duty. Direct payments start with the individual but have the potential to be extended to embrace the community; while the section 16 duty starts with the Welsh Government’s communitarian narrative but is anchored to the individual. Particularly when operating together, these two mechanisms create a space in which distinctly ‘Welsh’ forms of support – or even of independent living itself – might arise. Experiments with direct payment cooperatives have already taken place in both England and Wales,¹⁰¹ but the emphasis on mutual,

¹⁰¹ Alan Roulstone and Se Kwang Hwang, ‘Disabled People, Choices and Collective Organisation: Examining the Potential of Cooperatives in Future Social Support’ (2015) 30(6) *Disability & Society* 849. Roulstone and Hwang also consider developments in Sweden.

communitarian and collective responses in the public sector in Wales, together with the section 16 duty, create a unique environment for their potential development.

7. Discussion

The Act created a particular opportunity to examine the impact on the independent living counter-narrative when it became entwined with state policy. Various features were seen: an inability on the part of policy makers to understand independent living, a connection of independent living with independence, the use of independence in its broad meanings and a concomitant inclination towards master narratives of self-reliance, a disinclination on the part of the Welsh Government to promote individualism or to relinquish communitarian aspects of the Welsh Government narrative, the neutralisation and distortion of both colliding and adjacent narrative fragments of independent living, and an overwhelming of both independent living and the Welsh Government's own public sector narrative in the face of austerity.

The evidence of the Act and its supporting documentation is that the new, underlying master narrative of the legislation is sustainability – albeit layered over with the purported priority of wellbeing. While wellbeing – however that was understood – might be what policy makers sought for those using social care, it was not necessarily what they were able to create in the context of highly constrained spending. This circumstance resulted in the reduction or distortion of all fragments of independent living, including those that were adjacent to elements of the Welsh Government communitarian narrative. The Act also suggests, however, that if the resource context had been different, independent living would not necessarily be any better realised. It was clear that neither the content nor the purpose of independent living had been grasped by policy makers, and that master narratives were remaining extant as a result.

One possible reason for this was that the disabled people's movement had neither adequate opportunities to challenge misconceptions of independent living if and when they noted them arising, nor a 'champion' pushing internally for the understanding and acceptance of both independent living and the UNCRPD that

would be necessary for their acceptance. In addition, the approach to both the social model and direct payments demonstrated that while concepts might be nominally accepted or even embraced, those that are ‘difficult’ to the Welsh Government – whether because of colliding principles, conceptual complexity, or resources – were mentioned but not fully developed. While there is a desire for distinction from Westminster, there is also either a hesitancy in taking ideas forward, or a lack of the required capacity to do so, which undermines the potential radicalism of certain approaches in the Welsh context.

What was abundantly clear from the Act was that without some kind of traction that would enable independent living to be more effectively nudged into policy, the stubborn and powerful master narratives of otherness, deficit, dependency and care are unlikely to be effectively countered, or even incrementally shifted. In Welsh policy, the counter-narrative of independent living had become ‘lost’ – notionally on the Welsh Government’s radar, but as yet ineffective in terms of shifting master narratives. It was also clear from the Act that independent living had become wholly, and dangerously, entangled with the broader matter of independence. Earlier chapters have demonstrated that the confusion of independent living with independence was a contributory reason for the lack of understanding of the counter-narrative, and the Act confirmed that where the knowledge of this distinction fails, independent living is at risk. The problem was not simply that the use of the language of independence caused misunderstanding, that the separation of distinct ideas within the concept of independence was proving highly problematic, or that the master narrative was overwhelming, but that this master narrative was directly damaging to disabled people. Attempts to incorporate the idea of independence – genuinely believed by policymakers to be in the interests of those using social care – got drawn into a reified idea of self-reliance that was wholly antithetical to the counter-narrative.

8. Conclusion

Study of the 2014 Act demonstrated that, despite the largely contemporaneous development of the 2013 *Framework* by the Welsh Government, independent living

was not yet widely understood in either the Government or the Assembly and had not become a central plank of policy in the critical area of social care. It was also clear that the complexities caused by the use of the language of independence were creating difficulties and confusion and potentially putting the counter-narrative at risk. This difficulty was exacerbated by the financial climate of austerity, in which the Welsh Government's own principles were also severely compromised. The Act demonstrated that, broadly speaking, three things appeared to be needed for independent living to be successfully integrated into policy in the Welsh context. The first was a reiteration of the content of independent living to ensure that its content, and the intended meaning of independence, was fully understood by policy makers. The second was a 'reactivation' of the counter-narrative as a narrative of resistance and identity repair that rejects master narratives of deficit, otherness and 'care'. Finally, consideration was needed of ways in which a successfully 'repaired' identity and agency for disabled people – including the critical principles of individual choice and control – might effectively co-exist with the principles of collectivism that are valued by the Welsh Government and the disabled people's movement alike.

Chapter 12: Conclusion

1. Introduction

This thesis has examined independent living as an activist counter-narrative, developed by the disabled people's movement as an act of resistance to master narratives of deficit, otherness, dependency and 'care'. Specifically, it has examined what happens to that activist counter-narrative when attempts have been made to insert it into policy and law on adult social care and disability in Wales, where there is a focus on citizen and civil society participation in policy making.¹ This conclusion draws together some of the main points of the thesis and considers the issues and implications that arise in relation to counter-narrative theory, independent living and disabled people. This chapter also looks forward. It provides comment on the current proposals for the revised policy on independent living in Wales and indicates areas in which this project has highlighted a need for further research.

A counter-narrative is defined in this thesis as a narrative devised by a marginalised and oppressed individual or social group to effect identity repair and counter the difficulties that ensue from damaged identities: internalised harm, or the 'infiltrated self', and externally imposed damage, or the 'deprivation of opportunity'. The aim is to resist and challenge dominant social narratives that construct the oppressed group as inferior and enable structural oppression. A successful counter-narrative reconstructs a damaged identity in such a way that the agency of the oppressed person or group is liberated and their material opportunities are improved. This project has developed counter-narrative theory by identifying two distinct forms of counter-narrative, which had previously been 'hidden' in the literature. These have been termed 'everyday' and 'activist' counter-narratives. An activist counter-narrative

¹ Chapter 3, section 3.

is consciously devised by a marginalised group and deployed at a structural level in order to bring about social change.²

Where an activist counter-narrative is in play, change is in many cases sought at the level of national policy. Such policy has a powerful influence on narratives that exist within society, on the construction of identities of different social groups, and on the material opportunities available to those groups. The effective insertion of an activist counter-narrative into policy has the potential for significant organisational and cultural change for the benefit of the relevant group. In contrast, ineffective or partial absorption or the absorption of a distorted version of the counter-narrative is likely to restrict the potential for such improvements and may even cause further narrative damage. As counter-narrative theory had not previously been extended to this area, there was no analytical framework available to study the relationships between counter- and policy narratives. A framework of 'adjacency and collision' was therefore devised, to enable the use of counter-narrative theory to analyse the treatment of a counter-narrative in the policy context (Chapter 4). Adjacent fragments were those which were or appeared to be common to the counter-narrative and the policy principles. Colliding fragments were those which appeared to be dissonant or potentially oppositional.

The analysis of independent living as a counter-narrative has revealed three core clusters of fragments that made up central threads of the narrative, set out in Chapter 6. These have been termed 'personal agency', 'social agency' and 'equality and rights'. The analysis of the construction and use of independent living in the different datasets focused on these threads, the fragments within them, and the mechanisms that were created or identified as necessary by the disabled people's movement to enable them. The study demonstrated that the disabled people's movement has constructed independent living as a highly effective counter-narrative to the master narratives identified by activists. It also reveals that activists in Wales have held to this form of independent living, but have also developed emphases and elements which are particularly relevant and meaningful in the Welsh context (Chapter 7). In the Welsh DPM texts, independent living had certain differences of

² Chapter 4.

emphasis, particularly in relation to matters of communitarianism and the use of existing social care mechanisms. It had been found early in the research process that in the Welsh context, questions of individualism and communitarianism would be of particular importance in the analysis, and this was positioned as a central aspect.

2. Implications for independent living in the Welsh context

This study has demonstrated a number of implications for independent living in the Welsh context. The findings and analysis set out in Part III of this study show that certain aspects of the counter-narrative of independent living were largely neutralised and evaded when it was drawn into Welsh Government policy. This was the case even in the 2013 *Framework for Action on Independent Living*, which was intended to implement independent living in Wales. This does not mean that this evasion was intentional: the analysis indicates rather that it was a result of a combination of factors including misunderstandings, a reluctance or an inability to re-draw master narratives, and austerity (Chapters 10 and 11).

The project identified a fundamental collision between the necessarily individualistic element of independent living and the communitarianism that is prized in the Welsh context (Chapter 8). The study of independent living as a counter-narrative, reported in Part II of this thesis, demonstrated that it held an inclination towards individualism, encapsulated most strongly in the ideas of choice and control which formed the basis of personal agency. These fragments were definitional in the model of independent living developed in the texts from the Anglo-British disabled people's movement and also strongly present in the model constructed by the movement in Wales. Of the difficulties that arose from this collision, two were particularly significant. Firstly, and most obviously, the Welsh Government and the disabled people's movement were, to an extent, in an oppositional position, requiring negotiation around, and potentially compromise to, deeply held principles. Secondly, this situation required the disabled people's movement in Wales to find traction for the counter-narrative that did not depend on – and even potentially concealed or obscured – its defining thread of personal agency without undermining it.

Possibly as a response to this, the project has shown that the disabled people's movement in Wales has to date sought to develop a more communitarian approach to independent living in which individual choice and control are enabled through cooperative and collective approaches to social care, such as citizen-directed support, the cooperative use of direct payments and the use of 'traditional services', rather than the highly individual approaches of direct payments and personal assistance that have become central to independent living in the Anglo-British context (Chapter 7). Various questions arose from this that could not be explored within the parameters of this project and which require further research. One pressing question is how far the necessary individualism within independent living *can* be established, developed and supported through such communitarian structures and 'traditional services'. Projects are already ongoing in Wales³ and elsewhere in the UK⁴ which use communitarian approaches to social care, although the number of cooperatives using direct payments and adhering to independent living principles remains very small.⁵ Given the focus on direct payments as the means of enabling core elements of independent living in Wales, and the commitment to cooperative and communitarian methods in the Social Services and Well-being (Wales) Act 2014, further research into their potential, their impact, their drawbacks, the financial implications and resourcing needs is needed. Of equal importance is an up-to-date independent and comprehensive study of how direct payments are working in Wales: how easy they are to access and use, and how effectively they enable disabled people and others to live the lives of their choice.

A third core question that has emerged through this study is whether the model of independent living that has been forged in the Welsh context emerged in response to the wishes of disabled people or to the agenda of the Welsh Government. It is likely

³ See, for example, Disability Wales, 'Citizen Directed Co-operatives Cymru Project' (undated) <<http://www.disabilitywales.org/projects/citizen-directed-co-operatives-cymru-project/>> accessed 20 July 2019; Wales Cooperative Centre, 'Cooperatives for Care' (undated) <<https://wales.coop/co-operatives-for-care/>> accessed 20 July 2019; Leonard Cheshire 'Welsh Disabled People Take Control of their Care' (12 March 2019) <<https://www.leonardcheshire.org/about-us/press-and-media/press-releases/welsh-disabled-people-take-control-their-care>> accessed 20 July 2019.

⁴ Alan Roulstone and Se Kwang Hwang, 'Disabled People, Choices and Collective Organisation: Examining the Potential of Cooperatives in Future Social Support' (2015) 30(6) *Disability & Society* 849; Cooperatives UK and others, 'Owning Our Care' (*Cooperatives UK*, updated 25 May 2019) <<https://www.uk.coop/Owningourcarereport>> accessed 20 July 2019.

⁵ Roulstone and Hwang (n4).

that both aspects are in play. It is clear from the *Disability Wales Manifesto for Independent Living* that disabled people in Wales have articulated distinct priorities for independent living. It is equally obvious that the disabled people's movement in Wales is required for political reasons to respond to the Welsh Government agenda, just as the Anglo-British movement is required to consider the agenda in Westminster. The particular problem in Wales is the acknowledged weakness of the third sector in Wales and the lack of distance between the third sector and the Welsh Government.⁶ In this situation, the requirement to respond to governmental agendas may be existential as well as political, which is likely to have a particular impact on a small grassroots movement. A better understanding of these factors, the reasons for the differing priorities articulated by disabled people in Wales, the political levers that they can access and the impact of all these factors would shed light not just on independent living in the Welsh context, but also on the constraints and potential of the disabled people's movement and the state of the Welsh third sector more generally.

Despite these questions, this project demonstrates that there remains scope to explore a 'Welsh' form of independent living in which personal and social agency for disabled people are enabled through a public sector underpinned by communitarian rather than individualistic principles, giving voice to the collectivism that has historically been important to the disabled people's movement as well as the individualism that is central to independent living. The collision between the values of individualism and communitarianism that is potentially troublesome in the Welsh context arguably offers something new and distinctive in terms of consideration of how independent living might be enabled. John Evans – one of the pioneers of independent living⁷ – recently stated that co-production is the way forward for independent living in the UK⁸ – a practise that local authorities in Wales are now under a duty to promote under the 2014 legislation.⁹ It is likely in Wales that the predominant political principles will remain inclined towards mutuality and

⁶ Chapter 3, section 4.

⁷ See Chapter 2, section 4.

⁸ John Pring, 'Campaigner Pledges to Devote his Last Months to Saving Independent Living' (*Disability News Service*, 4 April 2019) <<https://www.disabilitynewsservice.com/campaigner-pledges-to-devote-his-last-months-to-saving-independent-living/>> accessed 11 April 2019.

⁹ Section 16.

communitarianism, creating genuine opportunities for the exploration of distinctive means to activate independent living. Such developments are by no means straightforward. They require an understanding of how genuine individualism – in the form of full and effective personal and social agency – can successfully be enabled through collective and communitarian approaches; and how equality can be achieved when public resources are profoundly constrained.

The requirement for the successful linguistic reclamation of independence, discussed in Chapter 8, also created particular difficulties for the counter-narrative. While this project considered these difficulties in the Welsh context, it was clear that they are relevant well beyond Wales. The counter-narrative derived many benefits from the deployment of the idea and language of independence – the connection with self-determination and autonomy, the sense of values shared between disabled and non-disabled people, and the power of independence as a motivating idea. In practice, however, the feat of linguistic reclamation was simply too complex to be successfully achieved – even within the movement itself. The difficulty of balancing the countering of and compliance with the master narratives of independence, and the power of these master narratives, meant that they were not effectively displaced (Chapters 8, 10 and 11). While activists in the Anglo-British context have argued that the language of independent living has been actively co-opted in Westminster, this study suggests that in Wales the difficulty is one of confusion rather than intention. It is noted in Chapters 2 and 7 that there is currently a debate in the disabled people's movement in the UK as to whether the phrase 'independent living' should be abandoned. Recommendations on that point are not for this thesis, but the findings of this study may provide information that is of value to that discussion.

3. The implications for disabled people and the disabled people's movement

The findings and analysis set out above hold significant implications for disabled people in Wales, particularly those who use or need assistance in their everyday lives. Independent living remains at the heart of the disabled people's movement in

Wales and the wider UK, and as a philosophy continues to demonstrate how disabled people can live the lives of their choice on an equal basis with others. The disabled people's movement in Wales has successfully worked with others, inside and outside the political institutions, to keep independent living on the policy agenda. However, this project has demonstrated clearly that despite this, Welsh policy on adult social care, disability and even independent living itself does not yet fully incorporate independent living as it is devised by the disabled people's movement. In Welsh Government policy independent living also remains attached to, and therefore incapable of successfully overturning, the master narratives that it is intended to counter (Chapters 10 and 11 in particular).

Overall, the findings of the project, particularly those reported in Part III of the thesis, suggest that while policy in Wales certainly includes elements of independent living, these could not reach their potential or do their work in the partial, compromised and incompletely understood form in which they were presented or while the master narratives relating to disabled people remained extant. As a result, the narrative repair of the identity and agency of disabled people, and the effectual countering of both the deprivation of opportunity and the infiltrated self is not yet fully achieved. This does not mean that no progress has been made, and a study of how far independent living has been practically implemented and enabled for disabled people in Wales would be of value in this context. Ultimately, however, this project has raised the question of whether the policy promoted in the studied documents and legislation yet has the capacity to secure the personal and collective outcomes of independent living envisaged by activists, and the ability of disabled people to live the lives of their choice on an equal basis with others. If not, questions remain as to where difficulties lie and whether these are difficulties of will, of understanding or of resources.

4. Looking forward: Action on Disability: The Right to Independent Living

In the spring of 2017 the Welsh Government announced its intention to undertake a review of the 2013 *Framework for Action on Independent Living*. This process was supported by a steering group comprising members of the third sector, chaired by Disability Wales. Disabled adults, young people and children, DPOs, third sector organisations and state agencies were consulted, and a consultation document, *Action on Disability: The Right to Independent Living* ('*Action on Disability*') was published by the Welsh Government in October 2018.¹⁰ Given the timing, it was not possible to incorporate a study of the consultation document into this thesis, although the author has produced a commentary which is available elsewhere.¹¹ The core points of that commentary are provided here.

Action on Disability incorporates a more comprehensive definition of independent living than its predecessor, drawing heavily on the longer explanation provided by Disability Wales in its 2011 *Manifesto for Independent Living*.¹² In contrast to the *Framework*, equality is emphasised and it is explicitly stated that independent living does not mean self-reliance or living alone. The definition also states that a right 'to practical assistance and support to participate fully in society on the same basis as others' is included in the meaning of independent living, although choice and control over this support is not mentioned.¹³ There is also extensive explanation of the social model of disability, which reflects the clearly greater inclination towards this counter-

¹⁰ Welsh Government, 'Consultation Document: Action on Disability: The Right to Independent Living' (22 October 2018) <<https://gov.wales/sites/default/files/consultations/2018-10/181018-action-on-disability-consultation-v1.pdf>> accessed 1 August 2019.

¹¹ Alison Tarrant, 'Action on Disability – The Right to Independent Living: A Critical Analysis' (2018) 2 Rhydian: Wales Social Welfare Law On-Line 31 <<http://www.lukeclements.co.uk/wp-content/uploads/2018/12/2018-08-Action-on-Disability-Final.pdf>> accessed 2 July 2019. This article was submitted in the response to the Welsh Government written by the author on behalf of the Cardiff University Centre for Health and Social Care Law. The article was also discussed at the meeting of the National Assembly for Wales Cross Party Group on Disability on 11 January 2019 and included in the consultation response of the Cross Party Group. See Cross Party Group on Disability, 'Minutes 11 January 2019' at <<http://www.senedd.assembly.wales/documents/s84035/Minutes%20of%2011%20January%202019.pdf>> accessed 1 August 2019.

¹² See Chapter 7, section 3.

¹³ Welsh Government, 'Consultation Document: Action on Disability' (n10) 10.

narrative on the part of the Welsh Government.¹⁴ Despite this more comprehensive definition of independent living, the document contains hints that the idea remains, to an extent, not fully understood, with the phrase ‘living independently’ connected particularly with housing.¹⁵ Ambiguous use of language persists – the terms ‘independent living’, ‘living independently’, and ‘independence’ are confused or used interchangeably. In addition, the term ‘independence’ is frequently used ambiguously,¹⁶ and is also used in relation to self-reliance.¹⁷ There is no discussion of the incorporation of the UNCRPD or a right to independent living into domestic legislation, despite ongoing calls for this from disabled activists¹⁸ and certain Assembly Members;¹⁹ and the explanation of the UNCRPD is even less complete than the partial description provided in the 2013 Framework.²⁰

The main body of the document is divided into four sections: an outline of the policy context, an outline of developments since the publication of the *Framework*, a summary of the issues raised in the consultation, and the commitments of the Welsh Government in relation to disabled people. Overall, the document indicates less connection with independent living as it was devised by the disabled people’s movement than was demonstrated in the *Framework*. Most notably, following the instructions of the then First Minister,²¹ the issues raised by disabled people are

¹⁴ Notably, workshops run by the Welsh Government in partnership with Disability Wales during the consultation process on the draft document also focused on the social model rather than independent living. Welsh Government, ‘Conversations following “Action on Disability: The Right to Independent Living” Consultation’ (5 June 2019) < <https://gov.wales/conversations-following-action-disability-right-independent-living-consultation> > accessed 1 August 2019.

¹⁵ Welsh Government, ‘Consultation Document: Action on Disability’ (n10) 18, 19 and 22.

¹⁶ For example: ‘We also want Wales to have a high quality and sustainable social care sector, with preventative and integrated services in the community, supporting people to lead independent lives’. Ibid 22.

¹⁷ For example, ‘This affected the ability of disabled people to use public transport independently but travel training could assist with this, at least where transport is available’. Ibid 25-26.

¹⁸ Disability Wales, ‘Disabled People’s Manifesto launch – Press Release’ (*Disability Wales*, 16 September 2016) <http://www.disabilitywales.org/disabled-peoples-manifesto-launch-press-release/> accessed 14 December 2018.

¹⁹ National Assembly for Wales Plenary Debate, Record of Proceedings, 10 October 2018, paras 255-307.

²⁰ Article 19 is paraphrased in almost precisely the same form as in the 2013 Framework (see chapter 10, Section 2), with the exception that the statement ‘Governments should do everything they can to ensure disabled people enjoy these rights’ has become ‘government recognises that disabled people should have these rights’ – a weaker obligation.

²¹ Welsh Government Disability Equality Forum, ‘Minutes: 19 July 2017, para 3.8. Available at < <https://gov.wales/sites/default/files/publications/2019-04/disability-equality-forum-minutes-19-july-2017.pdf> > accessed 1 August 2019.

grouped according to the Welsh Government's own policy aims²² rather than the priorities established by disabled people. While fragments of independent living continue to appear, *Action on Disability* contains no vision of the lives that disabled people can expect to lead, and no sense that disabled people are, or may be, active members of society, exercising their personal and social agency and enjoying a position in Welsh society as entitled and equal citizens living in local communities.

Despite the inclusion of a right to assistance and support in the definition of independent living, social care is sidelined in *Action on Disability*. The Social Services and Well-being (Wales) Act 2014 is not cited as part of the legislation that underpins Welsh Government action on disability,²³ although it is listed as a development that has taken place since the *Framework*. Concerns about social care provision raised during the consultation are listed in the document, some of which demonstrate significant risks to independent living. These include, for example, 'lower allocations for Direct Payments which means disabled adults and young people are becoming increasingly isolated'.²⁴ There is, however, no discussion on this theme, or other matters, such as the closure of the Welsh Independent Living Grant.²⁵ In contrast, the document has a strong focus on employment, which is noted to be an area of common interest to disabled people and the Welsh Government,²⁶ but does not reiterate the commitment in the *Framework* to individuals who are unable to work.²⁷

²² Four broad policy aims, or themes, are identified in the Welsh Government's programme for the Fifth Assembly. They are: 'Prosperous and secure', 'healthy and active', 'ambitious and learning', and 'united and connected'. Welsh Government, 'Taking Wales Forward: 2016-2021' (2016) <<https://gov.wales/sites/default/files/publications/2017-08/taking-wales-forward.pdf>> accessed 9 April 2019.

²³ The UNCRPD, the UNCRC, the Equality Act 2010 and the Well-being of Future Generations (Wales) Act 2015 are all cited as underpinning legislation.

²⁴ Welsh Government, 'Consultation Document: Action on Disability' (n10) 24. A Welsh disabled activist has commented on this, and on other matters of the treatment of social care in *Action on Disability*. See: John Pring, 'Welsh Government's 'Ludicrous' Failure on Independent Living Framework' (*Disability News Service*, 25 October 2018) <https://www.disabilitynewsservice.com/welsh-governments-ludicrous-failure-on-independent-living-framework/> accessed 14 December 2018.

²⁵ The Welsh Independent Living Grant (WILG) is the successor to the Independent Living Fund in Wales, although it has itself now been abolished. Information on the impact of the closure of the WILG and a campaign to save it can be found at <https://nathanleedavies.wordpress.com/save-wilg-campaign/> accessed 14 December 2018. See Chapter 2, section 4.

²⁶ Welsh Government, 'Consultation Document: Action on Disability' (n10) 6. Employment was also a particular focus of the responsible Minister when the Consultation Document was introduced to the Assembly. National Assembly for Wales Plenary Debate, Record of Proceedings, 16 October 2018, 305-312.

²⁷ Chapter 10, section 3.2.

Overall, Action on Disability suggests that the Welsh Government is regressing as much as it is progressing in its understanding of the purpose and content of independent living. The alignment of independent living with the Welsh Government's own policy ideals effectively wrests 'ownership' of independent living from the disabled people's movement, undermining its existence as a counter-narrative, neutralising its resistance and creating a risk that fragments that collide with the Welsh Government communitarian narrative may be set aside. The disengagement from social care as a critical enabler of independent living, together with the approach to employment suggests that the Welsh Government may be falling into narratives of self-reliance and economic productivity as a measure of individual worth that are prevalent at Westminster but antithetical to independent living. Ultimately, there is no real sense in the new strategy of the need to change narratives around disabled people.

5. Implications for an activist counter-narrative: The neutralisation of colliding and adjacent fragments and the lack of 'translation' of the purpose of resistance

The findings above pertain particularly to the matter of independent living in the Welsh context. Other findings from the study are more widely applicable, and likely to relate to other situations in which a social movement has attempted, or is attempting, to insert an activist counter-narrative into state policy at national or local level. The project demonstrates that, in the selected case study, both colliding and adjacent fragments were 'defused', but that this occurred in different ways. Colliding fragments were typically neutralised through evasion and modification (Chapters 9, 10 and 11). The fact of collision was not publicly discussed, and elements of personal agency were included, and even emphasised in policy relating to social care. However, although the ideas of control and, to a lesser extent, choice were visible, they often held little explicit content and tended to exist in a 'reduced' or qualified form. Choice was also confused and conflated with 'voice', which held similarities of meaning and resonance, but was allied with the Welsh Government's

own principles and was less powerful than choice in its impact for disabled people (Chapters 9 and 10). In addition, the fragments of choice, control, and independence-as-self-determination were consistently 'outsourced' to the enabling mechanism of direct payments, which remained connected to master narratives of deficit and otherness. This moderated both the radical potential of direct payments and also compromised the narrative of personal agency (Chapters 9-11).

Perhaps surprisingly, adjacent fragments were found to be even more problematic for activists seeking to insert the counter-narrative of independent living into policy. This study has demonstrated that adjacent fragments were neutralised by their ability to 'service' both the counter-narrative and the policy principles without significant challenge to the latter. This was partly as a result of their pre-existing pliability of meaning, which enabled their appearance in different narratives and thus their 'adjacent' status. This created difficulties on two distinct but connected levels. Firstly it enabled the appearance of consensus, despite a distinct heritage and, to an extent, content of the adjacent ideas. Secondly, it enabled the insertion of these fragments of the counter-narrative into the policy texts without any need to reconceptualise or challenge the underpinning master narratives or remodel the identities of disabled people (Chapters 10 and 11). The fragment of inclusion, for example, was vividly present in the *Framework* (albeit not in relation to social care) but also hazily invoked in that document as a generalised outcome without specific meaning. And in the 2104 legislation that same fragment of inclusion – together with that of a life in the community – took on an element of compulsion that was valuable to the Welsh Government agenda but is alien to the principles of independent living. Despite this distortion, the fragments of inclusion and community living also conveyed some of the substance of the fragment as it existed in the counter-narrative, placing it at risk and potentially undermining its content from within.

The project has also demonstrated that the incorporation of *fragments* of a counter-narrative in policy was ineffective in incorporating the counter-narrative as a whole and certainly ineffective in transplanting its purpose and intention. Nelson describes

master narratives as '*ensembles* of repeated themes'²⁸ and counter-narratives as a *woven* mass of narrative fragments (emphases added).²⁹ The documents from the disabled people's movement showed how, in relation to counter-narratives, this worked in practice. A number of repeated and developing thematic fragments, such as choice, control, inclusion and participation acted as a rich seam of intertwined ideas that together created new identities and agency of disabled people in such a way as to counter both the deprivation of opportunity and the infiltrated self (Chapter 6).

The analysis of the policy and legislative documents demonstrates that the presence of the same fragments in the Welsh Government documents was not in itself adequate to reproduce a similar narrative of resistance, or similar outcomes in terms of the reconstruction of the identities and agency of disabled people. There also needed to be an understanding of and a commitment to the oppositional purpose of the *combined* fragments as a means of resisting and shifting the underlying narratives, and a willingness to build a new identity and agency for the marginalised group. Without these, radical potential was systematically stripped from the fragments and the narrative more broadly (Chapters 10 and 11). The choice and control exercised over support through direct payments suggested in the *Framework*, for example, did not equate to independent living if the outcomes of an active and meaningful life on the individual's own terms were not also envisaged. In a policy context a counter-narrative might attack master narratives in one or both of two ways – the central intention of resistance might be embraced and the necessary fragments implemented to achieve the repaired identity, or fragments of the counter-narrative might be incorporated, take root and grow to overwhelm the master narratives. In Welsh Government policy and law neither path is yet occurring. As a result, master narratives were abraded in the policy documents but not successfully resisted and ultimately potentially even reinforced by their endurance against assault.

Again, it is not suggested that this was necessarily the *intention* of the policy makers. It is more likely that the Welsh Government wished to improve the quality of life for

²⁸ Hilde Lindemann Nelson, *Damaged Identities, Narrative Repair* (Cornell University Press 2001) 158.

²⁹ *Ibid* 6.

disabled people, but failed to understand the need for, or the necessary extent of, the narrative reconstruction of the identity and agency of disabled people, or even that independent living exists as a challenge to certain narratives and mechanisms. One contributing factor in this may have been that the disabled people's movement has become so familiar with the concept of independent living that its original purpose as a narrative of resistance is no longer at the forefront of its campaigning. It is noted in Chapter 6, section 3 that later documents emanating from the disabled people's movement, including those authored in Wales, tend to be less vivid, and to contain fewer explanatory passages that elaborate independent living. It is possible that neither the movement nor the Welsh Government noted the gulf between them in the understanding of independent living as an act of resistance, assuming that references to independent living reflected a mutual understanding of its content and *purpose*.

This raises the question as to whether a counter-narrative has the capacity to retain its subversive potential once it is brought into policy. In their discussions of the relationship between counter- and master narratives, set out in Chapter 4, section 7.2, counter-narrative theorists have identified the difficulty of a counter-narrative stepping onto the ground dominated by the master narrative. They suggest that relationships of compliance with the master narrative may constrain the ability of the counter-narrative to resist. They also point out that counter-narratives exist in relation to the master narratives that they oppose. The power of a counter-narrative lies largely within that existence as *opposition* and the narrative may lose meaning without that frame. It has been demonstrated earlier in this thesis that policy does not necessarily comprise a master narrative and may itself be an act of resistance.³⁰ At some level, however, the absorption of a counter-narrative into policy represents a form of 'mainstreaming' which in itself has the potential to undermine this character of resistance. In relation to independent living, for example, the insertion of independent living into social care policy requires, to an extent, an acceptance of, and compliance with, the system that has been heavily responsible for damaged identities, agency, the infiltrated self and the deprivation of opportunity. The study raises the question of whether independent living can ever work within that context,

³⁰ Chapter 4, section 4.

or whether something completely new is required. It is possible that the absorption of a counter-narrative into policy can only ever reproduce the counter-narrative accurately if the policy itself is actively intended to overthrow what went before.

It is noted in Chapters 1 and 3 that one of the reasons that policy in Wales was selected for study in this project was the requirement on the Welsh Government to devise policy in consultation with the third sector. The *Framework* was an example of policy generated in this context, stated by various parties to be co-produced by agencies including the Welsh Government and DPOs. One core learning that has emerged from this study is that these circumstances themselves are not adequate to ensure that the purpose and content of a counter-narrative can necessarily be shared, or perhaps fully understood, by different groups, even before the diverse needs of those groups are taken into account. If the counter-narrative is to be successful in policy, a shared commitment to its aims and to the resistance of master narratives is essential.

6. Conclusion:

This project has demonstrated that independent living – in the full form envisaged in both Wales and the wider UK disabled people’s movement – cannot be realised in policy without certain understandings. These include an understanding by all actors that independent living is not just a series of desired outcomes, but a means of redeveloping the identity and agency of disabled people that relies upon the emphatic rejection of master narratives of otherness, deficiency, dependency and care. In relation to Wales, the project has demonstrated that the incorporation of independent living into policy has been undermined by the persistence of the master narratives that it set out to counter. In Wales independent living is currently ‘suspended’ in an ideological battle between individualism and collectivism and losing coherent form as a result. In policy, independent living has been further undermined by austerity, which has resulted in the subjugation of the Welsh Government’s own public sector principles to financial constraints and a re-development of social care on principles of retrenchment and residualism that are antithetical to independent living. Moving forward from this position will require a re-

claiming of independent living by the disabled people's movement, a transparent discussion as to the ideological and resource constraints upon independent living that exist in Wales, and consideration of how apparently colliding principles can be resolved. If these can be achieved, there is scope for policy to be developed in Wales that animates independent living and enables disabled people to live the lives of their choice as full citizens on an equal basis with others.

Appendix 1: The texts in the datasets

Texts in the Anglo-British DPM dataset

Documents are listed in date order. 'Dissenting' texts are identified.

Paul Hunt, 'A Critical Condition' in Paul Hunt (ed), *Stigma: The Experience of Disability* (Geoffrey Chapman 1966).

UPIAS, 'Policy Statement' (1974 amended 1976)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-UPIAS.pdf>> accessed 16 November 2016.

UPIAS, 'The Union of the Physically Impaired Against Segregation and The Disability Alliance discuss Fundamental Principles of Disability' (1976)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-fundamental-principles.pdf>> accessed 16 November 2016.

AT Sutherland, *Disabled We Stand* (Souvenir Press 1981) (Chapter 7: 'The Role of "Disabled Person"').

Ken Davis, 'A Tenant's Eye View: The UPIAS Connection' (in UPIAS, 'Disability Challenge' Issue 1, May 1981)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UPIAS-Disability-Challenge1.pdf>> accessed 18 November 2016, 32-36.

Vic Finkelstein (writing as James Thorpe), 'A Question of Choice' (in UPIAS, 'Disability Challenge' Issue 1, May 1981)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-A-Question-of-Choice.pdf>> accessed 18 November 2016.

Ken Davis, 'Notes on the Development of the Derbyshire Centre for Integrated Living (DCIL)' (DCDP, December 1984)

<<http://disability-studies.leeds.ac.uk/files/library/DavisK-earlydcil.pdf>> accessed 1 June 2015. **(Dissenting text).**

Simon Brisenden, 'Independent Living and the Medical Model of Disability' (1986) 1(2) *Disability, Handicap & Society* 173.

Mike Oliver, 'Social Policy and Disability – Some Theoretical Issues' (1986) 1(1) Disability, Handicap & Society 5.

BCODP, 'Comment on the Report of the Audit Commission "Making a Reality of Community Care"' (August 1987)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/BCODP-report-of-audit-comm.pdf>> accessed 19 November 2016.

Colin Barnes, *'Cabbage Syndrome': The Social Construction of Dependence* (Falmer Press 1990) (Chapter 6: 'Participation and Control').

HCIL, 'HCIL Papers 1990: Independent Living' (1990)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-hcil.pdf>> accessed 16 November 2016.

The following papers presented at the BCODP seminar, 'Making Our Own Choices' (1992)

<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-making-our-own-choices.pdf>> accessed 13 July 2019.

- Stewart Bracking, 'Independent/Integrated Living - A Brief Overview'.
- Maggie Davis, 'Personal Assistance - Notes on the Historical Context'.
- Anne Rae, 'Independent Living, Personal Assistance and Disabled Women'.
- Nasa Begum, 'Independent Living, Personal Assistance and Disabled Black People'.
- Dennis Killin, 'Independent Living, Personal Assistance, Disabled Lesbians and Disabled Gay Men'.
- John Evans, 'The Role of Centres of Independent/Integrated Living and Networks of Disabled People'.

Ken Davis, 'The Disabled People's Movement: Putting the Power in Empowerment' (paper for seminar at Sheffield University 1996, updated 1998)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/DavisK-davis-empowerment.pdf>> accessed 18 November 2016.

Vic Finkelstein, 'Re-Thinking "Care" in a Society Providing Equal Opportunities for All' (discussion paper commissioned by the World Health Organisation, March 1998)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-finkelstein2.pdf>> accessed 18 November 2016.

Philip Mason, 'Back to Basics' (opening presentation at HCIL conference: Facing Our Future: Experts' Seminar on Independent Living and Direct Payments, July

1998) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/HCIL-facing-our-future.pdf>> accessed 18 November 2016.

Jenny Morris, 'The Meaning of Independent Living in the 3rd Millennium' (text of a talk delivered at University of Glasgow Centre for Disability Research, May 1999) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/morris-The-meaning-of-independent-living-in-the-new-millenium.pdf>> accessed 18 November 2016.

Tom Shakespeare, *Help: Imagining Welfare* (Venture Press 2000) (Chapter 4: 'Helpful').

(Dissenting text)

John Evans, 'Understanding Our Past and Controlling Our Future' (presentation at NCIL Forum, 12th July 2001) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/evans-Understanding-our-Past-and-Controlling-our-Future.pdf>> accessed 18 November 2016.

Mike Oliver, 'Where Will Older People Be? Independent Living versus Residential Care' (Conference: The Care and Management of Older People with Complex Needs, London, June 2001) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Oliver-where-will-older-people-be.pdf>> accessed 21 September 2017.

Jenny Morris, 'Independent Living and Community Care: A Disempowering Framework' (2004) 9(5) *Disability & Society* 427.

Gerry Zarb, 'Independent Living and the Road to Inclusion' in C Barnes and G Mercer (eds), *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004).

Colin Barnes, 'Independent Futures: Policies, Practices and the Illusion of Inclusion' (presentation to ENIL, November 2006, unpublished) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Barnes-valencia-presentation-Colin.pdf>> accessed 18 November 2016.

Vic Finkelstein, 'The "Social Model of Disability" and the Disability Movement' (2007) <<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/finkelstein-The-Social-Model-of-Disability-and-the-Disability-Movement.pdf>> accessed 2 January 2017.

(Dissenting text)

Peter Beresford, *What Future for Care?* (Joseph Rowntree Foundation 2008).

Jane Campbell, 'Fighting for a Slice, or for a Bigger Cake?' (The 6th Annual Disability Lecture, St John's College, University of Cambridge, April 2008)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/Campbell-Fighting-for-a-slice-of-the-cake-FINAL-FINAL-29-04-08.pdf>> accessed 16 November 2016.

Debbie Jolly, 'Personal Assistance and Independent Living' (ENIL paper, 2010)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/jolly-Personal-Assistance-and-Independent-Living1.pdf>> accessed 10 November 2016.

Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011).

Disability Rights UK, 'Consultation Response on "Fulfilling Potential: Disability Strategy" (9 March 2012),
<<https://www.disabilityrightsuk.org/sites/default/files/pdf/fulfillingresponse.pdf>> accessed 2 January 2017.

Disability Rights UK, 'Joint Committee on the Draft Care and Support Bill: Written Submission' (11 January 2013)
<<https://www.disabilityrightsuk.org/sites/default/files/pdf/jointcommitteeresponse.pdf>> accessed 2 January 2017.

Inclusion London, 'Disabled People's Manifesto: Reclaiming Our Futures' (2013)
<<http://pf7d7vi404s1dxh27mla5569.wpengine.netdna-cdn.com/files/library/UK-Disabled-People-s-Manifesto-Reclaiming-Our-Futures.pdf>> accessed 2 January 2017.

Inclusion London, 'Evidence of Breaches of Disabled People's Rights under the UN Convention on the Rights of Persons with Disabilities' (2015)
<<https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/equality-and-human-rights/evidence-of-breaches-of-disabled-peoples-rights-under-the-un-convention-on-the-rights-of-persons-with-disabilities/>> accessed 2 January 2017.

Texts in the Welsh DPM dataset

These texts are listed in date order and the text written by an author not known to be disabled is identified.

Disability Wales / Anabledd Cymru, 'Manifesto for Independent Living' (2011)
<http://www.disabilitywales.org/wordpress/wp-content/uploads/Manifesto_for_IL_E.pdf> accessed 11 November 2016.

Disability Wales / Anabledd Cymru (on behalf of Partner Organisations),
'Consultation response, Health and Social Care Committee Social Services and Well-being (Wales) Bill' (March 2013)
<<http://www.senedd.assembly.wales/documents/s15186/SSW%2015%20Partner%20Organisation%20co-ordinated%20by%20Disability%20Wales.pdf>> accessed 10 November 2016.

Letter from Vin West on behalf of Arfon Access Group / Grwp Mynediad Arfon to Sarah Beasley, Clerk to Health & Social Care Committee, (15 March 2013)
(accepted as a response to the consultation on the Social Services and Well-being Wales Bill)
<www.senedd.assembly.wales/documents/s15313/SSW%2043%20Arfon%20Access%20Group.pdf> accessed 2 January 2017. **(Written by an author not known to be disabled)**

Disability Wales / Anabledd Cymru, 'Disabled People's Manifesto' (2016)
<<http://www.disabilitywales.org/wordpress/wp-content/uploads/DW-Manifesto-BILINGUAL-FINAL.pdf>> accessed 9 November 2016.

All Wales People First, 'Manifesto 2016' (2016)
<<http://allwalespeople1st.co.uk/resources/manifesto-2016/>> accessed 2 January 2017.

Disability Wales / Anabledd Cymru, 'Written Evidence Submitted to the Joint Committee on Human Rights (IL 39)' (27 April 2011). Published in, Joint Committee on Human Rights, 'Implementation of the Right of Disabled People to Independent Living: Written Evidence' (2011) <https://www.parliament.uk/documents/joint-committees/human-rights/Independent_Living_Written_Evidence_4.pdf> accessed 15 July 2019, 164-169.

Texts in the WG dataset

These documents are listed in date order. The Welsh Government was originally known as the Welsh Assembly Government. The relevant name is given here as it appears on the face of the document.

Welsh Assembly Government and NHS Cymru, 'Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care' (2002) <<http://www.wales.nhs.uk/sitesplus/documents/829/WAG%20-%20Creating%20a%20Unified%20and%20Fair%20System%20for%20Assessing%20and%20Managing%20Care.PDF>> accessed 21 June 2019.

Welsh Assembly Government, 'Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance Wales 2004' (2004) <<http://www.wales.nhs.uk/documents/direct-payment-policy-e-merge.pdf>> accessed 21 June 2019.

Welsh Assembly Government, 'Fulfilled Lives, Supportive Communities: A Strategy for Social Services in Wales over the Next Decade' (2007) <<http://gov.wales/dhss/publications/socialcare/strategies/fulfilledlives/fulfilledlivese.pdf?lang=en>> accessed 23 February 2018.

Welsh Assembly Government, 'Statement on Policy & Practice for Adults with a Learning Disability' (2007) <<http://gov.wales/docs/dhss/publications/100126policyen.pdf>> accessed 23 February 2018.

Welsh Assembly Government, 'Sustainable Social Services for Wales: A Framework for Action' (2011) <<http://gov.wales/docs/dhss/publications/110216frameworken.pdf>> accessed 23 February 2018.

Welsh Government, 'Consultation Document: Social Services (Wales) Bill' (2012) <<http://gov.wales/docs/dhss/consultation/120312consultationen.pdf>> accessed 23 February 2018.

Welsh Government, 'Framework for Action on Independent Living' (2013) <<http://gov.wales/docs/dsjlg/publications/equality/130916frameworkactionen.pdf>> accessed 23 February 2018.

Abbreviations

BCODP:	British Council of Organisations of Disabled People
DCDP:	Derbyshire Coalition of Disabled People
DCIL:	Derbyshire Centre for Integrated Living
ENIL:	European Network on Independent Living
HCIL:	Hampshire Centre for Independent Living
NCIL:	National Centre for Independent Living
UPIAS:	The Union of the Physically Impaired Against Segregation

Appendix 2: The selection criteria applied to the authorship of the DPM Datasets

Given the large number of documents available for study from the Anglo-British disabled people's movement, and the need to obtain a sample that was representative and provided a 'snapshot' of the movement, the following criteria were applied in the selection process.

Authors should explicitly identify as being connected with the disabled people's movement

As the focus of the thesis was on the counter-narrative of independent living, as identified and developed by the disabled people's movement in the UK, it was necessary to select works from individuals and groups who recognised this movement and considered themselves to have some form of connection with it.

The dataset included works by a variety of authors, including key activists and 'thinkers' with a range of experiences

This enabled a broad range of viewpoints to be studied.

The maximum number of documents from a single author was restricted to three

This prevented the distortion of results by over-reliance on the work of one individual or DPO.

Authors should have some 'representative' characteristic

As far as was possible, where the author was an individual, works were selected in which they had some representative capacity, such as speaking on behalf of an organisation. Such works were considered to be representative of the views of a broader group.

To be written by individuals in England and Wales and in English

As the thesis related to the Welsh context, works relating to the development of independent living in other nations, including those specific to Scotland, were discounted. Quotes from individuals or organisations outside the UK that occurred in the texts were included in the coding and analysis. Where commented upon in the thesis, such quotes are indicated. Where Welsh documents were bilingual, only the English sections were included.¹

Documents authored by the Disability Rights Commission / Equality and Human Rights Commission were not included

The Disability Rights Commission (DRC) merged into the Equality and Human Rights Commission (EHRC) in 2007. While it has had an influence on the development of independent living, it is not a DPO and there were occasions when distinctions were drawn by authors between the Commissions and DPOs.² Documents authored by the Commissions were therefore not included in the dataset. There was one exception – a document authored by Gerry Zarb, acting in a DRC capacity, was included owing to its relevance to the subject matter and Zarb's personal history of activism.³

Gender and minority experiences

An attempt was made to include works by male and female authors and which considered issues pertaining to particular minority groups. Men were more heavily represented among the high profile speakers and thinkers of the movement in its early years, and little detailed information was available on the minority experience. Three texts relating to the female, BME and LGBTQ experiences were available in

¹ See Chapter 1, Section 5.

² Evans states, 'the important thing is that *we are* in control of this process and not the Disability Rights Commission' (original emphasis). John Evans, 'The Importance of CIL's In Our Movement' (presentation, 2nd November 2006 <<http://pf7d7vi404s1dxh27mla5569.wengine.netdna-cdn.com/files/library/evans-Valencia-CIL-Presentation-john.pdf>> accessed 22 February 2018, 2.

³ Gerry Zarb, 'Independent Living and the Road to Inclusion' in Colin Barnes and Geof Mercer (eds), *Disability Policy and Practice: Applying the Social Model* (The Disability Press 2004). The document does not state that Zarb was writing in a DRC capacity. It was written by Zarb at the time that he held the position of Head of Health and Independent Living at the DRC and states 'The discussion [in this document] is set in the context of the Disability Rights Commission's (DRC) ongoing work on establishing a right to independent living'. The document discussed, among other matters, the importance and prospects of developing a legal right to independent living at the time that the UNCRPD was being negotiated.

the form of presentations at a 1992 BCODP conference, all of which were included. In the final Anglo-British DPM dataset 15 of the included authors were male, six were female and six were DPOs. The Welsh DPM dataset comprised documents authored by DPOs and one male author.

Appendix 3: The coding structures

Table 1: UK DPM Dataset coding scheme

Nodes (parent nodes in bold)	Child node (parent nodes in bold)	Child node
Nodes relating to independent living (IL)		
The history of IL		
IL as a creation of the DPM		
IL as a social / international movement or as an organising principle for the movement		
IL as an aspiration for disabled people		
IL as a concept 'owned' by disabled people or as a user-led concept		
IL as relevant to all disabled people		
IL extending to groups other than disabled people		
Future needs for IL		
Threats / hindrances to IL		
Resource questions		
Connection between IL and adult social care		
IL as a policy aim or outcome		

Language of IL (including references to contested meanings and 'appropriation' of IL)		
IL beyond the UK		
IL in a quote		
Governmental references to IL		
IL as self-sufficiency (references to 'IL skills' etc)		
References to CILs		
References to the ILM		
IL in a title or a name		
The personal outcomes / experience of IL		
	A meaningful life (rather than an existence)	
	Access	
	Change in an individual life	
	Control	
	Choice	
	Community living or non-institutionalism	
	Dignity	
	Education	
	Employment and / or an economic identity	
	Flexibility in one's life	
	Freedom	
	Home	
	Inclusion / integration	
	Individuality of each person	
	Living separately from family	

	Participation	
	Personal relationships	
	Personal development	
	Self-determination	
	Self-respect	
	Self-responsibility	
	Wellbeing	
Enablers of the personal outcomes		
	Access	
	Advocacy / Self-advocacy	
	Aids, adaptations, technology or equipment	
	Co-production	
	Counselling	
	Direct payments	
	Health care	
	Housing	
	Income	
	Independent living 'services' or 'schemes'	
	Individual determination	
	Information and advice	
	Peer support	
	Personal assistance	
	Self-directed support	
	Support	
		Support in the community

		The need of support in daily life
		Personal approaches to support
		The need for all or any appropriate support
		Collective approaches to support
	Training	
	Transport	
Citizenship aspects of independent living		
	Citizenship	
	Equality	
	Non-discrimination	
	Rights	
		References to Article 19 CRPD
	Value or worth of disabled people	
Theoretical aspects of independent living		
	IL as a challenge / response	
	IL as a philosophy / ideology / theory	
	IL as a way of life	
	Individualism / consumerism	
	Political aspects	
	Social model	
Nodes relating to independence		
Independence in relation to IL		

	Synonymous with IL	
	Self-reliance	
	Ambiguous in this regard	
Governmental discussion of independence		
	Reference to governmental discussion of independence	
	Governmental undermining of DPM construction of independence	
	Governmental use of DPM language	
Discussion of language or the meaning of 'independence'		
IL in a quote		
Non-institutional (or non-family) living		
Young people moving into adulthood		
IL in a name or a title		

Table 1a: UK DPM Dataset (dissenting texts) coding scheme

Nodes relating to independent living	
The history of independent living	
Independent living as a creation of the disabled people's movement	
Independent living as an international movement	
Independent living embracing all disabled people and extending beyond disabled people	
Independent living as a challenge to traditional ideas / models	
Critique of independent living	
Alternatives to independent living	
The language of independent living	
References to integrated rather than independent living	
Independent living in a quote	
Independent living as a service model	
ILM reference	
CIL reference	
In a name / title	
Personal outcomes of independent living	
	Choice
	Control
	Inclusion
	Participation

	Self-determination
Enablers of the personal outcomes	
	Direct payments
	Personal assistance
Citizenship aspects of independent living	
	Rights / Entitlement
	Equality
Theoretical aspects of independent living	
	Independent living as a challenge to other models / ideas
	Independent living as a philosophy
	Individualism / consumerism
	Social model
Nodes relating to independence	
Consideration / critique of the DPM focus on independence	
Alternatives to a focus on independence	
The language of independence	
The values attached to independence	
Independence in a quote	
Independence in a name / title	
Independence in relation to IL (parent node)	
	Independence used synonymously with IL
	Independence as self-reliance
	References to independence that are ambiguous in this regard

Table 2: Welsh DPM Dataset coding scheme (extracts beyond which IL was directly referenced*)

Node (parent nodes in bold)	Child node
Nodes relating to independent living	
IL as an organising principle	
IL as an aspiration of the DPM or a disabled person	
IL as relevant to all disabled people	
Future needs for IL	
Threats or hindrances to IL	
Resource questions	
Connection between IL and adult social care	
IL within or as government policy	
The language of IL	
IL in a quote	
Government discussion or references to IL	
References to CILs	
In a title / name	
Personal outcomes / experience of IL	
	A meaningful life
	Access
	Choice
	Control
	Community living
	Dignity

	Education
	Employment and/or having an economic identity
	Freedom
	Home
	Inclusion
	Participation
	Respect
	Self-determination
	Self-responsibility
	Voice
	Wellbeing
Enablers of the personal outcomes	
	Access
	Advocacy
	Aids, adaptations, technology and equipment
	Citizen-Directed Support
	Collective or cooperative approaches
	Co-production
	Direct payments
	Disabled people's organisations
	Housing
	Income
	Individualised / person-centred support
	Information and advice
	Outcomes-focused approaches

	Peer support
	Personal assistance
	Personalisation / Personal budgets
	Self-directed support
	Social care
	Transport
Citizenship aspects of independent living	
	Citizenship
	Equality
	Human value or worth
	Rights or entitlements
Theoretical aspects of independent living	
	Social model
Nodes relating to independence	
Independence in relation to independent living	
	Self-determination
	Self-reliance
	Ambiguous in this regard
Governmental discussion of independence	
Discussion of language or the meaning of 'independence'	
Independence in a quote	

* The coding structure for extracts in which independent living was directly referenced was identical, with certain codes absent and one extra code included. The extra code was 'cultural identity' as an outcome of independent living.

Table 3: WG Dataset coding scheme: Documents prior to the *Framework*

Nodes (parent nodes in bold)	Child node (parent nodes in bold)
Nodes relating to fragments of independent living	
Fragments of independent living: Personal outcomes	
	A meaningful life
	Choice
	Community life
	Control
	Dignity
	Education or training
	Employment
	Family life
	Freedom
	Having one's own home
	Health
	Inclusion / integration
	Participation
	Respect
	Self-determination or autonomy
	Self-respect
	Taking part in decisions or processes
	Voice

	Wellbeing
Enablers of fragments of independent living	
	Access (including access to services)
	Advocacy
	Aids, adaptations, technology and equipment
	Cooperatives / social enterprise
	Co-production
	Direct payments
	Housing
	Information
	Peer support
	Person centred or individualised approaches
	Personal assistance
	Personalisation / Personal budgets
	Self-assessment
Fragments of independent living: Citizenship	
	Citizenship
	Equality
	Rights
	Worth in society
Theoretical elements of independent living	
	Social model
Prevention of need	
Risk	
Universalism	

Use of language that conflicts with that of the DPM	
Nodes relating to independence	
Independence in relation to independent living	
	Self-determination
	Self-reliance
	Ambiguous in this regard
	Implying both self-determination and self-reliance
Financial independence	
Non-institutional living	
Young people moving into adulthood	

Table 4: WG Dataset coding scheme: The Framework for Action on Independent Living

Nodes (parent nodes in bold)	Child node (parent nodes in bold)	Child node
Nodes relating to independent living		
The personal outcomes of independent living		
	A meaningful life	
	Access	
	Choice	
	Community living	
	Control	
	Education and training	
	Employment	
	Freedom	
	Home	
	Inclusion	
		Inclusive design
	Participation	
	Self-determination	
	Voice	
	Wellbeing	
Enablers of the personal outcomes		
	Access	
	Access to services	
	Advocacy	

	Aids, adaptations, technology or equipment	
	Citizen-directed support	
	Community	
		Community as an enabler
		Community based services
		Universal community services
	Cooperatives or collective models	
	Co-production	
		Co-production on Framework
		DPM priorities (refs to)
	Direct payments	
	DPOs (including access groups)	
	Housing (including refs to adaptations)	
	Information and advice	
	Outcomes focused approach	
	Peer support	
	Personal assistance	
	Person centred support	
	Public sector other than social care	
	Social care	
	Technology	
	Transport	
	WG actions or plans	
Citizenship aspects of independent living		
	Citizenship	

	Equality	
	Rights	
Theoretical elements of independent living		
	Social model	
Other		
Independent living as a service model		
Need for a shift in attitudes		
Sustainability / Resources		
Welsh Government		
	Limit to WG capacity	
	WG plans and strategies	
	WG priorities	
Wider social benefit of IL		
Nodes relating to independence		
Independence in relation to IL		
	Self-determination	
	Self-reliance	
	Ambiguous	
	Both	
Non-institutional living		
Young people moving into adulthood		

Appendix 4: Code books

Code book 1: The Anglo-British DPM dataset

This code book sets out the codes used in the Anglo-British DPM Dataset. It is divided into two sections: the code book for extracts relating to independent living, the code book for extracts relating to independence.

Section 1: The codes relating to independent living

The code	How the code was applied
The history of IL.	Include references to the development / history of independent living AND to the development / history of the disabled people's movement more widely. Only include allusions to IL in other countries (eg: the US) if there is a clear link between that and the development of IL in the UK. (Note that two ideas are conflated here, which would need separation if this code were to be followed up for detailed analysis).
IL as a creation of the DPM	There must be a specific reference to the fact that independent living was created by the DPM or by disabled activists. Do not include references to the fact of control or 'ownership' of IL by disabled people unless there is also a reference to its heritage.
IL as a social or an international movement / an organising principle for a movement	Include references to IL as an international phenomenon and where IL is forming the basis for a movement or is the aim for which a movement is working.
IL as an aspiration for disabled people or for the DPM.	Use only where there is a particularly strong focus on or an explicit reference to the importance of IL to disabled people.

IL as a concept that is 'owned' or controlled by disabled people or 'user-led'	Include explicit references to the need for IL to be or to remain a user-led concept. This is distinct from references to how IL was developed by disabled people.
IL as relevant to all disabled people / the inclusion of all disabled people	Include references to how independent living is, or should be, or is becoming relevant to all disabled people and / or what is needed to ensure that all disabled people can benefit from it.
IL as something that extends to wider groups of people (eg: to groups such as older people).	Include references to how other groups might benefit from IL and to the impact of independent living beyond the disabled person – eg: when independent living (or the failure of independent living) has an impact on other family members.
Future needs for IL	References to what is needed to encourage the growth of independent living, or for independent living to be achieved by more people or by other groups of people (eg: BME groups, or people with particular impairments).
Threats or hindrances to IL	Include simple references to the existence of threats / hindrances / barriers to IL as well as more substantive references to what those threats are. Include references to past threats as well as to future ones. Do not include references to resourcing issues – code these to 'resource questions'.
Resource questions	Only include questions of whether things are resourced or not, or discussion of lack of resources or rationing. Include references to where resources are strained or inadequate.
Connection between IL and community care or to the ASC structures.	Use where the reference connects IL to community care or to adult social care. IL might be seen as an outcome of the ASC structures, or the ASC system could be seen as failing to create IL. Include references where CC / ASC systems are not explicitly referenced but are included or implicit in more general references to 'support structures' or policies.
Independent living as a policy aim or outcome.	Include references where there is a <i>failure</i> to make IL a policy outcome.
Language of IL or references to contested meanings of IL.	Include all references to discussion of the language of independent living, including as to questions of suitability of language. Include references to the appropriation of the language and / or ideas of the DPM (if language use is part of that process of appropriation).
IL beyond the UK	Include references to IL in other countries, implicitly as well as explicitly (eg: where individuals / organisations have learnt from others in other countries).
Independent living in a quote	Include all extracts that occur in a quote or which refer to other people's ideas on independent living. If the extract refers to other people's ideas / views on IL, only code elsewhere if the quote or view is being cited as an example of the immediate author's own thinking.
Governmental references to IL	Include all references to governmental discussion of IL, or quotes from government documents referring to IL. Do not code these to any other codes.
IL as self-sufficiency or capability	References to 'independent living' as the ability to look after oneself, or to functional capability (eg: a reference to independent living skills).

CIL reference / ILM reference	Use where there is any reference to CILs or to the ILM. Where the reference to the CIL or to the ILM contains substantive comment on the content of independent living, the reference can be double (or multiple) coded accordingly.
In a title	Use for all references in a title or a name. These can only be double coded if there is a strong link to another concept – eg: there is a sub-heading in a document such as “The right to independent living”.

The meaning or content of independent living

In the coding structure, these codes were split into four areas: personal outcomes, enablers of the personal outcomes, citizenship aspects, and theoretical outcomes.

Personal outcomes (parent node)	
A meaningful life (rather than an existence)	Include extracts in which there are explicit references to having a life that goes beyond an existence, or to having a meaningful life and extracts in which a life with meaning and content is otherwise expressed. Include, for example, references to one’s ‘lifestyle’ and to things such as leading an active or fulfilled life. Include references to things that would typically be included as part of a fulfilled life, eg: sexuality. Include references to one’s ‘everyday life’. Include references to the denial of a meaningful life.
Access	References to access must be coded as <i>either</i> an outcome or an enabler but cannot be coded to both. Include references to barrier removal (if they are references as an outcome, rather than an enabler).
Change in an individual life	Include references where there is discussion of eg: individual progression or development.
Control	Include references to control over support. Do not include references to self-determination unless the notion of control is specifically also mentioned or emphasised. Do not include references to self-directed support unless control is explicitly discussed. Include references to the denial of control.
Choice	Choice over life and support. Do not include references to self-determination unless the notion of control is specifically mentioned or emphasised. Do not include references to self-directed support unless choice is explicitly discussed. Include references to the denial of choice.
Community living or non-institutionalism	Include references to community places such as schools or shops etc, even if there is no direct reference to community living. Do not include references to, eg: getting a job – there has to be some sense of community ‘place’. Include references to non-institutionalisation. Include references to the denial of community living.
Dignity	Only include references where this word is used.

Education	Include all references to education and training, regardless of whether they are to education as an outcome or as an enabler. Include references to the denial of education.
Employment and / or an economic identity	Include all references to employment, regardless of whether they are to employment as an outcome or as an enabler. Include references to a person having an economic identity / capability / presence (other than as a user of direct payments). Include references to the denial of employment.
Flexibility in one's life	Include references to flexibility of support.
Freedom	Include references to freedom of movement. Include references to the denial of freedom.
Home	Include references to having one's own home or having the home of one's choice etc. Do not include references to accessible or adapted housing (code these as 'housing') <i>unless</i> there is also the sense of the outcome of the home of one's choice.
Inclusion / integration	Include all references to inclusion eg: inclusion in the community. Include references eg: to inclusion in aspects such as employment <i>only</i> if there is some implicit or explicit reference to inclusion in non-segregated settings eg: 'in the real world' or 'on equal terms with others'. Do not include references to participation unless the idea is explicitly mentioned (code these separately). Include references to the denial of inclusion.
Individuality of each person	Include references that demonstrate or demand that each person is able to express their individuality.
Living separately from family	Include references to the right / ability of or the need for people to live separately from their family. Include references to the right not to have support provided by family members.
Participation	Include all references to participation eg: participation in the community or participation in aspects such as employment. There must be some implicit or explicit reference to participation in non-segregated settings eg: 'in the real world' or 'on equal terms with others'. Do not include references to inclusion unless the idea is explicitly mentioned (code these separately). Include extracts that refer to making a social / community contribution or similar. Do not include references to participation in 'service' development (code those to co-production). Include references to the denial of participation.
Personal relationships	Include references to partners and family relationships.
Personal development	Include references to the right or opportunity to develop or grow as a person.
Self-determination	Include references to autonomy. Do not code these also to choice and control unless those words are explicitly used and / or the ideas are specifically emphasised in the extract. Include references to self-directed support. Include references to the denial of self-determination.
Self-respect	Include references to self-worth, overcoming negative feelings in this area, and connected ideas.
Self-responsibility	Only include references where this idea is explicitly referenced. Do not include references to eg: choice or control unless there is a clear statement relating to self-responsibility.
Wellbeing	Only include extracts if this word is explicitly used.

Enablers of the personal outcomes (parent node)	
Access	References must be coded to either access as an outcome or as an enabler but not both. Here code references to how access enables people to have the lives of their choice, or to take part in activities etc. Include references to access to specific things (eg: accessible transport, accessible buildings, accessible housing). Include implicit references eg: references to barrier removal. Include references to universal / inclusive design.
Advocacy / self-advocacy	Include all references to formal and informal advocacy and to self-advocacy. If the reference is specifically to peer advocacy, place it in the code for peer support.
Aids, adaptations, technology or equipment	Include general and specific references to adaptations, including housing adaptations. Include all references to aids, technology, equipment etc, whether talking about use, funding etc.
Co-production	Include all extracts that refer to joint working on policy, support structures etc – the word ‘co-production’ does not need to be present.
Counselling	Include all references to counselling, other than to peer counselling, which should be placed in the code for peer support.
Direct payments	Include ‘implicit’ references to direct payments, or to what became direct payments (eg: to ‘cash’ to buy one’s own support. Do not include references to personal budgets.
Health care	Include all references to health care.
Housing	Only code here housing as an enabler – not the right to have a house, or to have a home of one’s own or of one’s choice. Include references to accessible housing, including to suitability of housing, and to the need / use of adaptations.
Income	Include all references to earned or other income.
Independent living ‘services’ or ‘schemes’	Include all references to IL ‘schemes’, including those which appear to be similar to eg: supported living.
Individual determination	Include all references to the need for individual determination or resilience as an enabler of independent living.
Information	Include references to the accessibility of information.
Peer support	Include all references to peer support, eg: peer advocacy or counselling. Include references to peer training, knowledge and networking.
Personal assistance.	Only include specific references to personal assistance, not general references to individualised support etc.
Self-directed support	Code also to ‘self-determination’ as this is implicit in self-directed support, but not to choice or control unless those ideas are explicitly referenced.

Support	Parent node, see below
Training	Include references that are explicitly to education or training as an enabler of IL, including references to education or training in lists of the 'pillars' of IL. Do not include references to 'independent living skills' where these relate to the capacity to accomplish a task. Place such references in the code for 'IL as self-sufficiency or capability'.
Transport	Include references to accessible transport.
Support (parent node)	
Support in the community	Include all references to the need for support to be provided in community or non-institutional settings. References can also be coded to community living if appropriate. Do not include references to direct payments or personal assistance.
The need for support in daily life	These are general references to the fact of a need for support in daily life for many people. Do not include references to something specific like PA, generalised support etc.
Personal approaches to support	References to the need for individualised support but not references to personal assistance.
The need for all and any appropriate support	Include all references to the fact that individuals need whatever support that is necessary to the particular individual if they are to achieve independent living.
Collective approaches to support	Include any references to ideas for how support that enables IL could be provided in collective ways.
Citizenship aspects (parent node)	
Citizenship	Include explicit references to citizenship or where there is some form of engagement in civic or political life. Ideas that are connected to citizenship (eg: equality) should be placed in the specific codes which come under this parent heading.
Equality	Include all references to equal opportunity, equal rights etc. Include references to sameness or equivalence (eg: disabled people want the same things as non-disabled people / disabled people should expect to be treated as their non-disabled peers).
Non-discrimination	Include explicit references to discrimination / IL as a means of countering discrimination etc and particular forms of discrimination – eg: at work, hate crime etc.
Rights	This code includes references to both a right / entitlement to independent living and references to IL as a right / entitlement to something else / one of its component parts (eg: 'IL is about our right to control our own lives'. (Initial efforts were made to separate these out, but the distinction was often unclear, so the codes for these two notions were merged). Include references to rights or entitlements to specific things, such as housing.

	Do not include references to Article 19 or the UNCRPD unless the author explicitly states that Article 19 is an expression of IL or it is clear that the author is using Article 19 as an expression of IL.
Value or worth of disabled people	Include any references to the general concept of the value of disabled people.
Theoretical aspects (parent node)	
IL as a challenge / response	Include references to where IL is an explicit or implicit challenge to other forms of support, the underlying ideas, or power structures.
IL as a philosophy / ideology / theory	Include any explicit references to IL as a philosophy, or references to IL as a framework encompassing multiple ideas, if there is some sense of IL being an abstract idea as well as a practical series of outcomes.
IL as a way of life	Include any references that suggest that IL is a way of life, a path etc.
Individualism / consumerism	Include references to where IL is seen to contribute to or has a theoretical or historical basis in individualism / consumerism.
Political aspects	Include references eg: to whether IL is politically charged or politically neutral.
Social model	Include all references to the social model. References to barriers or barrier removal should be placed in access.

Section 2: The codes relating to independence

Independence in relation to independent living (parent node)	
Synonymous with 'independent living'.	Use this when it is clear that the reference is to the same notion of independent living (eg: when independent living is already under discussion and the reference to independence is obviously connected; or where a phrase such as 'living independently' is used as a stylistic device to avoid 'independent living'). NB: There were no separate references in this dataset to independence as self-determination.

	Do not code to any other of the codes relating to independence in relation to IL.
Self-reliance.	<p>Include all references where the author implicitly or explicitly relates independence to various forms of self-reliance. Include references to:</p> <ul style="list-style-type: none"> • The lack of a need for state support; • The lack of the need for any other forms of support; • Financial self-reliance; • Functional ability or the ability to carry out tasks alone; • The ability to do things (eg: travel) alone. <p>Include both 'positive' and 'negative' references (eg: references where there is a lack of self-reliance). Do not code to any other of the codes relating to independence in relation to IL.</p>
Ambiguous in this regard	<p>This code is used in relation only to the particular focus in this analysis as to distinctions between 'self-reliance' and 'self-determination'. It must be applied where there is a lack of clarity as to which of these main concepts 'independence' is embracing.</p> <p>Use this code where the substantive meaning of 'independence' is not specified and / or 'independence' could relate to either self-determination or self-reliance or both.</p> <p>NB: This code must be strictly applied. It must only be used where there is genuine ambiguity or lack of specification in the meaning. If the context is sufficient to place a reference into the code for either 'synonymous with IL' or 'self-reliance', the reference must be coded accordingly. However, it must be used if the relationship between independence and one of the other codes is too tenuous for that coding to be rigorous (ie: if placing the reference in one of the other codes is too subjective).</p> <p>Do not code to any other of the codes relating to independence in relation to IL.</p>
Reference to governmental discussion of independence (parent node)	
Governmental discussion of independence	<p>Use when the reference to independence does not reflect meanings invested by the immediate author, but the text is considering what government (or policy) means when discussing independence. Include quotes from Government sources.</p>

Governmental 'attack' or undermining of DPM construction of independence	Include references to governmental refusal / disinclination to use the language of independence as it is understood by the DPM, or use of the concept of independence by Government that appears to undermine this idea.
Governmental use of DPM language	Include references to / discussion of the use of the language of 'independent living' by government or other agencies.
Other nodes relating to independence	
Discussion of the language or of the meaning of 'independence'.	Use when the concept or meaning of <i>independence</i> is under discussion, including discussion of the use of the language of independence by the IL movement / within IL. Include instances where the specific use isn't necessarily about how language is used, but the overall context is in this area.
Independence in a quote and references to other people's views of independence.	Use when there is a quote to 'independence' from another document or an individual. Include references to other people's thoughts or opinions. These can be double-coded to the above if the author is using the quote to demonstrate their own point or is otherwise endorsing it. Quotes from government sources or policy documents must not be included here. They should be placed in the code for Government references to 'independence'.
Non-institutional or non-family living	Use when the reference is to living outside an institutional setting and / or to references to the need / desire not to receive support from the family, or to be forced to live with family because no other options are available.
Young people moving into adulthood	Use only for references to independence or 'gaining independence' where this refers to a young person taking on adult responsibilities, or moving into adulthood.
In a name or title.	Use these when the reference is simply part of a title or in a name, such as Personal Independence Payment. These references cannot be double / substantively coded.

Code book 2: The dissenting documents

This table only includes instances where the coding was distinct from the other texts in the Anglo-British DPM Dataset (ie: the codes were only used in dissenting documents or where the code was used differently in some way from its wider use in the Anglo-British DPM dataset).

Independent living	
Critique of IL	Include extracts in which there is commentary on the content / values of IL (not necessarily 'critical') and also discussion of problems that are or may be related to independent living.
Alternatives to independent living	Include discussion of concepts that the DPM could pursue either as an alternative to or to complement the focus on independent living.
References to integrated rather than independent living	Include references to integrated living and discussion of the perceived distinctions between 'integrated' and 'independent' living.
Independence	
Critique of the DPM approach	Include extracts in which there is commentary on the focus on independence / discussion or questioning of the impact and outcomes of a focus on the idea of independence. Include issues arising from the focus on independence.
Alternatives to a focus on independence	Include references to ideas that the DPM could pursue instead of the focus on 'independence'.
The values attached to independence.	Include extracts in which there is explicit or implicit discussion of the values attached to the idea of independence.

Code book 3: The Welsh DPM Dataset

This table only includes instances where the coding was distinct from that of the Anglo-British DPM Dataset (ie: the codes were only used in documents in the Welsh DPM dataset, or where the use of the code was different in some way from its use in the Anglo-British DPM dataset).

Personal outcomes of independent living (parent code)	
Respect	Include explicit and implicit references to respect by others of disabled people. Do not include references to self-respect.
Voice	Include references to individual or collective voice, and negative references as well as positive ones (ie: concern about the idea of 'voice' as well as acceptance of it).
Enablers of independent living (parent code)	
Citizen-directed support	Include all references to CDS.
Collective / cooperative approaches	Include any references to collective and cooperative approaches (including CDS, but extending beyond these)
DPOs / CILs	Include all references to all forms of DPOs both in general and to specific organisations.
Outcomes-focused approaches	Include all references in which 'outcomes-focused' approaches or support are explicitly referenced.
Personalisation	Include references to 'personalised' support and / or personal budgets only – not references to person-centred support / individualised support etc.
Social care	Include all references to social care other than to direct payments / personal assistance.

Code book 4: Welsh Government dataset

This table only includes instances where the coding was distinct from codes set out above (ie: the codes were only used in documents in the Welsh Government dataset, or the use of the code was different in some way from its use elsewhere).

The comments on the overall coding of the WG Dataset (Appendix 5) are relevant to this element of the code book. These comments indicate that coding was applied more broadly to the Welsh Government documents than in the other datasets. The reasons for this expansion are given in Appendix 5.

Independent living	
Prevention of need	Include any references to the need or importance of preventing need arising or becoming exacerbated.
Risk	Include all extracts that discuss risk, including any relating to safeguarding or the balance of need with outcome and / or risk.
Universalism	References which relate to the need or provision of universal services
Use of language that conflicts with the language used by the DPM	Include any references that use language that differs from language use in the DPM, eg: references to 'vulnerability', 'normal patterns of living', 'their disabilities' etc.
Personal outcomes of independent living (parent node)	
Communities	Include all references to communities – whether to do with community life and the inclusion of people using support, or other references, such as the need to support communities as well as individuals, community safety etc.
Family life	Include all references to the need for or existence of a family life
Taking part in decisions	Include references here to individuals taking part in decisions about their life which pertain to, but do not extend to having, choice or control over those decisions.

Enablers of the personal outcomes (parent node)	
Access to services	Include references to access that have to do solely to access to services
Cooperatives / social enterprises	Include references to 'social enterprise' in addition to collective or cooperative arrangements.
Social care support or 'services'	Include all references to support that comes through the social care system or to social care 'services'. Do not include references to direct payments or personal assistance unless there is also a specific reference to social care.
Independence	
Independence in relation to IL (parent node)	
Independence as self-determination	Include references in which independence can clearly be related to the idea of self-determination. In the Framework for Action on IL include references to independence that are synonymous with IL in this code. Do not code to any other of the codes relating to independence in relation to IL.
Both self-determination and self-reliance	Include references that appear clearly to apply to both these aspects (rather than those which are ambiguous as to which they apply). Do not code to any other of the codes relating to independence in relation to IL.
Financial independence	Include references to a person's financial independence. Do not code to any other of the codes relating to independence in relation to IL.

Code book 5: Codes used in the Framework for Action on Independent Living

This table only includes instances where the coding was distinct from codes set out above (ie: the codes were only used in documents in the Welsh Government dataset, or the use of the code was different in some way from its use elsewhere).

The comments on the overall coding of the WG Dataset (Appendix 5) are relevant to this element of the code book. These comments indicate that coding was applied more broadly to the Welsh Government documents than in the other datasets. The reasons for this expansion are given in Appendix 5.

Independent living	
IL as a service model	Include any references that are, or appear to be, to IL as some form of 'service' model.
Shift in attitudes	Include any references for a need in a shift of attitudes towards disabled people (whether of the Welsh Government, state agencies or among the public) if IL is to be accomplished, or in general.
Resources and sustainability	Include any references to resources, including references to the need for sustainability of public resources.
Wider social benefit of IL	Include all references to the benefits of IL beyond disabled people, including to communities or society more widely or to other groups of individuals
Welsh Government (parent node)	
Limit to the WG competence	Include any specific and explicit references to the restrictions on the competence of the WG to take action on matters related to IL.
WG plans and strategies	Include all explicit references to named WG plans, strategies, policy documents etc.
WG priorities	Include all references to the priorities that exist within the Welsh Government communitarian narrative
Personal outcomes of independent living (parent node)	

Inclusive design (child of the node 'Inclusion')	Include any specific references to inclusive or universal design
Enablers of the personal outcomes (parent node)	
Community as an enabler	Include any references in which the community itself (not community services) are seen as an enabler of the personal outcomes for disabled people.
Co-production on the Framework (child of node 'Co-production')	Include all references to the co-productive approach to the Framework, including references to consultation etc.
DPM priorities (child of node 'Co-production')	Include any implicit or explicit references to the priorities or values of the DPM
DPOs	Include all references to CILs or other DPOs and references to groups that are stated in the document to be DPOs.
Universal community services	Include all references to community services that are not disability specific.

Appendix 5: Detailed information on the coding process

Throughout the coding process various judgements had to be made as to how the coding should be undertaken. For example, questions arose as to whether references to centres for independent living (or CILs) should be coded as references to independent living, whether repeated references should be coded, and so on. In many of these situations there were both advantages and disadvantages to coding extracts in one way, rather than another, with no 'right answer'. This appendix sets out how certain coding issues were dealt with and provides information to supplement Chapter 5.

Coding the Anglo-British DPM documents

Delineating the extracts to be coded

Restricting the coding of the Anglo-British DPM documents to extracts where these words appeared increased the rigour of the coding procedure but was also problematic. In many documents there were sections of text in which independent living was discussed that were larger than the extracts in which those words appeared. These whole sections could arguably have been coded. Expanding the coding in this way created a difficulty in delineating where this should start and stop. For reasons of the transparency and replicability of the study, the coding was therefore restricted to sections of the text where the relevant words appeared.

The overlap between certain ideas and themes, and specific matters of substantive coding

Certain ideas overlapped. For example, self-determination or autonomy inherently contain the ideas of choice and control, and the ideas of inclusion and participation are inherent in

the theme of employment. Similarly, many references to equality included ideas such as inclusion and participation. If extracts were consistently coded to all of these themes, there was a risk of the coding becoming so vague as to be meaningless. To overcome this as far as possible the following steps were taken:

- Extracts were only coded to a theme if there was explicit discussion of it or it was inseparable from the content.
- References to self-determination or autonomy were not also coded to choice and control unless those words were also explicitly used or the ideas specifically emphasised in the text (and vice versa).
- References to 'self-directed' support (or similar) were coded to self-determination, but not to choice or control unless those ideas were more explicitly present in the extract.
- References to equality were not coded to ideas such as participation and inclusion unless those ideas were also explicitly present or somehow emphasised.
- References to inclusion and participation had to contain some specific implicit or explicit reference to the idea. For example, a reference such as: 'active lives at work, rest and play' would be coded to employment and to 'having an active life' but not to inclusion or participation. However, if there was a reference to, for example, accessing pubs or cinemas, or the use of phrases such as: 'in the real world' or 'on equal terms', inclusion and participation were considered to be engaged as there was an explicit or implicit reference to activity in non-segregated settings.
- References to an individual's control over their own lives or their own support was cited as 'control', but references to disabled people having control over their own organisations was not.
- Extracts were only coded to citizenship if this word was explicitly used, or there was explicit reference to civic life or political engagement.

The overlap between outcomes and enablers

Certain ideas were expressed as both an outcome and an enabler, eg: access or employment. It was not always possible to identify which of these ideas was dominant.

Different ideas were coded in different ways, as below:

- All references to employment were placed into one code, which was considered an outcome.
- References to access were split into two codes: 'access as an outcome' and 'access as an enabler'.
- The ideas of 'home' and 'housing' were separated, with ideas connected to having one's own home coded as an outcome and the matter of accessible, suitable or adapted housing coded as an enabler.
- References to education were separated, with some references (typically to training) coded as an enabler and others (typically to education) coded as an outcome.

References to Article 19 of the UN Convention on the Rights of Persons with Disabilities

In Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) the phrase 'living independently' rather than 'independent living' was consciously adopted. Article 19 is therefore not automatically synonymous with the idea of independent living as it is expressed within the UK. References to Article 19 were therefore only placed into the code for 'rights' under the parent code of independent living if the author expressly connected Article 19 to independent living (for example: 'Article 19 deals with the right to independent living' (Jolly, 2010)). All other references to Article 19 were placed in a separate code. However, given the close connection between independent living and Article 19, in the analysis both these codes were ultimately examined and considered together. They are brought together in the tables of results.

References to 'living independently'

References to 'living independently' were coded to independence rather than to independent living. Where these were synonymous with independent living, this was expressed within the relevant code under the master code for independence. References that were synonymous with the idea of independent living were not also coded as independent living.

Multiple references to independent living or independence

The words 'independent living' or 'independence' were frequently referenced repeatedly in sequential sentences or the same sentence. There was a risk of inflating particular themes if every reference was separately counted substantively to the same code. As a result:

- References were not separated if they were items on a list. For example: 'So now we see independent living bungalows, independent living aids and appliance centres, independent living homes, independent living advisers, independent living research...' (Mason, 1998).
- If there were two or more consecutive sentences in which the same theme was under consideration, both containing the phrase 'independent living', these were only coded separately if there was a clear intention to repeat the statement for emphasis or if distinct ideas were present. For example, the extracts below are sequential but were coded as two separate references in relation to rights. The first reference was considered to relate to the need to promote a right to independent living, while the second set out how this might be done and connected independent living to Article 19.

"We note the significant disadvantage to disabled people which persists in relation to choice and control and levels of participation in economic and social life and the impact this has on their economic and social well-being, and on what many of our witnesses considered to be their enjoyment of basic human rights. We therefore welcome the Government's recognition that more progress is required to promote disabled people's right to independent living."

The Government should continue their commitment to delivering independent living by ensuring that the forthcoming Disability Strategy sets out a clear plan of action to make progress with regard to independent living as defined by Article 19, with milestones and monitoring mechanisms. The Disability Strategy should build on and update the outcomes framework set out in the current Independent Living Strategy.”

Similarly, references in the same sentence were only coded separately if an idea was explicitly repeated or took on a different dimension. For example, ‘Without Independent Living we do not have our Human Rights and without Human Rights we do not have Independent Living’ (Evans, 2001).

Sequential extracts were not split up and coded separately where pronouns (it, this) were used to refer to independent living – in these cases there was typically a sense of one ‘continuous thought’ by the author.

References to independent living or independence in names, titles and references to Centres for Independent Living (CILs) and the Independent Living Movement (ILM)

- References to independent living or independence in headings, sub-headings, titles and names were not substantively coded. Names included references to the Independent Living Fund (ILF), the Personal Independence Payment (PIP), the names of government strategy documents and the names of non-DPO organisations (for names of DPOs, see immediately below).
- Names of DPOs, such as specific CILs or networks (HCIL, ENIL etc) were coded as a reference to a CIL. References to the independent living movement or ILM were coded as references to the ILM. References to both of these were also substantively coded if they contained information that shed light on independent living.
- References to the ILM in other countries, including the US and / or internationally were only substantively coded if the document implicitly or explicitly indicated that the ideas of the non-British movement overlapped with or derived from those of the movement in the UK.

- References to the Derbyshire Centre for *Integrated Living* (DCIL) were not substantively coded as references to independent living (even where substantive information was contained in the extract) unless DCIL was explicitly referred to as a Centre for *Independent Living* or connected to independent living by the author.

The use of pronouns

- Where 'it' (or other signifiers, such as 'this development') referred to independent living or a CIL or the independent living movement, they were coded as such. As far as possible, references where pronouns were used were coded in a larger extract where the term 'independent living' or 'independence' also appeared.

Coding the Welsh Government Framework for Action on Independent Living

Overall, the coding was applied in a less constrictive way in the *Framework for Action on Independent Living* than in the documents from the Anglo-British and Welsh DPM datasets – that is, that if a reference was 'marginal' in whether it applied to a particular code, it was coded. The reason for this was to obtain as much information as possible as to how the Welsh Government understood ideas that were being articulated and promoted by the disabled people's movement. Overall, these documents were also coded more broadly – if an idea occurred twice in a sentence or paragraph, the biggest unit was coded as one reference.

The *Framework* was also subject to some very broad coding. Particularly in relation to the enablers of independent living, the *Framework* is divided into long sections that relate to a particular idea eg: transport, access to the built environment, or housing. Such sections were coded as a block to the relevant idea, split into their component sections (eg: issues or evidence). The reason for this was to ensure consistency and transparency, rather than to be reliant on how many paragraphs existed, or how many times the relevant idea was

actively referred to. The exception to this were the sections on information and advice, advocacy and peer support, as the bulk of information here was on information and advice. In those two sections, the entire sections were coded 'in bulk' to information and advice and the individual paragraphs relating to advocacy and peer support were separately placed in those codes. A table setting out the sections that were 'block coded' is provided in Appendix 8 alongside the other coding of the *Framework*.

Appendix 6: Tables of results: Anglo-British DPM dataset (excluding dissenting texts)

Table 1: Personal outcomes of independent living

The desired or intended personal outcome of independent living	Number of references in which this outcome was connected to independent living	Number of sources in which this outcome was connected to independent living
Rights (including all references to Article 19)*	111	17
Control	61	20
Choice	56	20
Equality	54	16
Community living (including references to non-institutional living)	44	14
Having a meaningful life	43	18
Inclusion / integration	37	16
Participation	28	14
Self-determination	22	11
Employment and/or an economic identity	19	12
Citizenship	16	8
Personal relationships	9	6
Freedom	9	5
Home	8	5
Access (as an outcome, not as an enabler)**	7	4
Education	6	5
Self-responsibility	3	3
Living separately from family	3	2
Self-respect	2	2
Personal development or change in one's own life	2	1

Flexibility in one's life	2	1
Human value or worth	2	1
Individuality of each person	2	1
Dignity	1	1
Changes in individual lives	1	1
Wellbeing	1	1

* Rights are not strictly an outcome of independent living but are included in this table for convenience. The complex relationship between rights and independent living is discussed in Chapter 6.

** Many references to access were not explicit as to whether access was seen as an outcome or an enabler of independent living. In all such cases, access was coded as an enabler.

Table 2: Enablers of independent living

The enabler of independent living	Number of references in which this enabler was connected to independent living	Number of sources in which this enabler was connected to independent living
Personal assistance	67	17
Access	37	15
Direct payments	36	12
Peer support (other than through CILs)	30	11
Support*	19	11
Appropriate housing	12	10
Transport	10	8
Advocacy / Self-advocacy	10	6
Information and advice	8	7
Self-directed support	8	6
Aids, adaptations, technology or equipment	7	7
Training	7	5
Co-production	6	4
Health care	4	4
'Independent living services' or 'schemes'	4	2
Counselling	3	3
Income	2	2
Individual determination	1	1

* References to support that are distinct from references to how support is to be achieved (eg: via personal assistance or having choice and control over support). They include:

Support in the community	6	5
The need for support in daily life	5	5
Personal or individualised support	4	3
All and any appropriate support	2	2
Collective approaches to support	1	1

Appendix 7: Tables of results: Welsh DPM Dataset

Table 1: Personal outcomes of independent living (extracts in which independent living was directly referenced)

The desired or intended personal outcome of independent living	Number of references in which this outcome was connected to independent living	Number of sources in which this outcome was connected to independent living
Choice	16	5
Rights or entitlements	15	3
Having a meaningful life	11	5
Control	9	4
Equality	8	3
Inclusion	5	2
Community living (including any references to non-institutional living)	5	2
Participation	5	2
Citizenship*	3	3
Dignity	3	3
Employment and/or having an economic identity	3	1
Wellbeing	3	1
Access (as an outcome rather than an enabler)**	2	1
Freedom	1	1
Home	1	1
Respect	1	1

* Not including references to citizen-directed support.

** Many references to access were not explicit as to whether access was seen as an outcome or an enabler of independent living. In all such cases, access was coded as an enabler.

Table 2: Enablers of independent living (extracts in which independent living was directly referenced)

The enabler of independent living	Number of references in which this enabler was connected to independent living	Number of sources in which this enabler was connected to independent living
Access	8	2
Personalisation	4	2
Peer support	4	2
Citizen-Directed Support	4	2
Individualised or person-centred support (including references to self-directed support)	3	3
Advocacy	3	2
Information and advice	3	2
Transport	3	1
Direct payments	2	2
Aids and adaptations	2	1
Housing	1	1
Personal assistance	1	1
Training	1	1

Table 3: Allusions to the outcomes of independent living across the documents as a whole*

The outcome of independent living	Number of references to this outcome	Number of sources in which this outcome was referenced
Choice	63	5
Rights	47	5
Control	43	5
Having a meaningful life	36	6
Equality	33	5
Inclusion	27	4
Community living	25	5
Participation	24	4
Citizenship	23	6
Employment or an economic activity	14	3
Education	10	2
Voice	9	4
Wellbeing	9	3
Self-determination	6	4
Self-responsibility	5	2
Dignity	4	4
Freedom	4	3
Home	4	3
Human value or worth	4	3
Respect	4	2
Access (as an outcome not an enabler)**	3	1

* These references include those in which independent living was explicitly referenced.

** Many references to access were not explicit as to whether access was seen as an outcome or an enabler of independent living. In all such cases, access was coded as an enabler.

Table 4: Allusions to the enablers of independent living across the documents as a whole*

The enabler of independent living	Number of references to this enabler	Number of sources in which this enabler was referenced
Access	28	5
Co-production	21	5
Information and advice	19	3
Personalisation	13	3
Social care	15	3
Direct payments	14	5
Collective or cooperative approaches	14	4
Advocacy	11	4
Citizen-directed support	10	4
Peer support	9	4
An outcomes focused approach	11	4
Transport	8	2
CILs or DPOs	7	4
Self-directed support	6	3
Person-centred support	4	2
Adequate income	4	2
Housing or living arrangements	3	2
Personal assistance	3	2
Aids, adaptations, technology or equipment	3	1
Counselling or emotional support	3	1

* These references include those in which independent living was explicitly referenced.

Appendix 8: Tables of results: WG dataset

Table 1: References to fragments of independent living in the documents prior to the Framework for Action on Independent Living (personal outcomes)

The outcome of independent living	Number of references to this outcome (in all documents)	Number of references in the Learning Disability Strategy	Number of sources in which this outcome was mentioned
Choice*	83**	16	6
Community life	68	25	6
Control*	62**	3	6
Citizenship	56	12	4
Inclusion / Integration	47	24	6
Active and meaningful life	44	23	5
Voice	42	1	4
Rights / entitlements	41	12	4
Wellbeing	39	3	5
Family life	30	3	5
Equality	28***	23	4
Self-determination	21	7	5
Employment	21	11	4
Participation	20	13	5
Education	19	8	5
Home	11	2	5
Self-respect	5	4	2

* In addition, there were 25 references to the involvement of individuals in arrangements or decisions about them which did not extend to the matter of the person having choice or control over the situation.

** Of the 83 references to choice, 38 appeared in the 2002 Direct Payments Guidance. In addition to the 62 references to control, there were 17 references to managing one's own direct payments, or one's own support via direct payments in

one source (the 2002 Direct Payments Guidance). Thirteen of the 62 references to control appeared in the Direct Payments Guidance.

*** In addition, there were ten references to equal access to or outcomes from services and five references to equality duties in statute, equality strategies, etc.

Table 1a: Fragments of independent living that appeared in the Learning Disability Strategy but no other documents

Fragment	Number of references
Health	23
Worth in society	6
Dignity	2
Respect	2
Freedom	1

Table 2: References to fragments of independent living in the documents prior to the Framework for Action on Independent Living (enablers)

The enabler of independent living (other than references to social services, social care, or other public services)	Number of references to this enabler	Number of sources in which this enabler was mentioned
Direct payments	130*	6
Access to services	64	6
Person centred or individualised support	60	6
Information	25	5
Advocacy	20	6
Co-production	19	5
Housing	9	3
Peer support	9	3
Personal assistance	8	1 (the 2002 Direct Payments Guidance)
Self-assessment	6	4
Aids, adaptations, technology or equipment	5	3
Personalisation or personal budgets	5	3
Access (other than access to services)	2	1 (the 2007 Statement on Learning Disability)
Cooperatives or social enterprise	2	1
Social care and other public sector support	Uncountable**	

* Of these 130 references, 118 were in the 2002 Direct Payments Guidance, and 12 in the remaining documents.

** As the majority of these documents were about social care / social services, references to social care and to other elements in the public sector were essentially uncountable.

Table 3: The personal outcomes in the Framework for Action on Independent Living

The personal outcome of independent living	Number of references
Inclusion	72*
Choice	38
Participation	38
Equality	34*
Community	30*
Rights	29*
Employment	28 ^
Having a meaningful life	28
Education	22
Control	18
Wellbeing	17
Being at or having a home	16
Access	11 ^
Voice	9
Self-determination	8
Citizenship	6
Freedom	1

* (Community): There were also three references to the community as an enabler of independent living, eight to universal community services and four general references to communities.

* (Inclusion): There were also 11 references to inclusive design.

* (Equality): There were also 20 references to 'all' or 'everyone', six of which had a particularly strong sense of equality; and 18 references to strategies, plans or legislation that related to equality.

* (Rights): There were also five references to legislation or Welsh Government strategy that relates to rights.

^ Denotes a fragment that was also block coded (see Table 5 below).

Table 4: Welsh Government Documents: The enablers in the Framework for Action on Independent Living

The enabler of independent living	Number of references
Access	97
Co-production	36*
Information and advice	22 ^
Transport	20 ^
Public sector (other than social care)	20
DPOs	19** ^
Adult social care (including references to direct payments)	18 ^
Technology (including references to specialist technology and equipment and to universal technology, such as internet use)	17 ^
Direct payments	15
Person centred or individualised support or technology	15
Peer support	11
Housing (including references to adaptations)	8 ^
Access to services	8
Advocacy	7 ^
Personal assistance	3
Citizen-directed support	2
Outcomes-focused approach	2

* There were also 20 references to the co-productive process undertaken for the development of the Framework, including eight references to the consultation process on the Framework.

** There were also three references to access groups, which are considered in the Framework to be DPOs.

^ Denotes a fragment that was also block coded (see Table 5 below).

Table 5: Block coding in the Framework for Action on Independent Living

The numbers in the tables above include the following sections of the Framework that were coded in 'blocks'

Section title	Block coded to which code/s	Number of blocks coded
Access to good quality and accessible information and advice	Information and advice	1
Improved access to independent advocacy services	Advocacy	1
Improved access to adapted and accessible housing	Housing	1
Disabled people having more control over their lives by being able to make choices in the care and support they receive	Social care	1
Improving access to technology that supports independent living	Technology	1
Improving access to public transport	Transport	1
Improved access to buildings, streets and public places	Access as an outcome	1
Increased employment rates for disabled people	Employment	1
An increase in the number of disabled people having access to a Centre for Independent Living ⁸ in Wales	DPOs	1
Section 4.1: Information, advice, advocacy and peer support	Information and advice (not advocacy or peer support)	4
Section 4.2: Housing	Housing (not access)	3
Section 4.3: Personalised care and support	Social care	3
Section 4.4: Person-centred technology	Technology	3
Section 4.5: A barrier-free transport system	Transport Access as an enabler	4 4
Section 4.6: Accessible and inclusive places	Access as an outcome	5
Section 4.5: Employment	Employment	4

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