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Independent Living as a Counter-Narrative

A Work of Resistance and Repair

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ABSTRACT

This article explores the concept of independent living as a counter-narrative. I argue that in addition to being both an aim for disabled people and a campaign objective for the global disabled people's movement, independent living also acts as a narrative tool that opposes majoritarian social constructions of disability and creates 'repaired' identities for disabled people. I analyse documents produced by the disabled people's movement in the UK to establish how independent living performs the work of resistance and re-draws social identities to enable equality and social justice for disabled people. I suggest that if independent living is to be effectively enshrined in domestic law and policy, the challenge it poses to dominant social narratives must be fully understood, and consider the role of the UN Convention on the Rights of Persons with Disabilities in effecting this.

KEYWORDS

Independent living; disabled people's movement; disability; counter-narrative; UN Convention on the Rights of Persons with Disabilities; social model of disability; social movement

1. Introduction

Independent living has been described as one of the 'big ideas' of the disabled people's movement.¹ It emerged as a grassroots, 'bottom-up' idea in the 1970s and 1980s, as disabled people struggled against institutionalisation and exclusion. Independent living articulates the ideas of equality, ambition, freedom, inclusion and self-determination as they relate to disabled people. Its essential principle is the right of disabled people to live on an equal basis with others – in control of their lives, living in the place of their choice, and pursuing their own ambitions. In 1986, the UK independent living pioneer Simon Brisenden stated:

We desire a place in society, participating as equal members with something to say and a life to lead; ... If we are to be treated as individuals who are due the same respect as other people, then we must

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be allowed to choose a way of living that confronts all the options and risks throughout life that are inherent to living in, rather than outside, society.²

Independent living is more than an aim. The UK disabled people's movement also describes it as a philosophy,³ a way of life,⁴ and a form of challenge and resistance.⁵ Much of the current commentary on independent living focuses on its status as a goal and a set of outcomes for disabled people, exploring how these may be attained, threats to their realisation and problems of implementation.⁶ There has been less exploration in recent years of what independent living achieves in terms of resistance, why this matters and difficulties that emerge when attempts are made to insert independent living into the policy context. This article fills this gap. I position independent living as a counter-narrative, developed and deployed by disabled activists to reject externally created majoritarian constructions of a socially acceptable 'disabled identity' that has facilitated the exclusion and objectification of disabled people, and consider whether this countering work is effective. I focus in particular on two aspects of independent living. Firstly, I examine its role in developing a place for the individual within the collective approaches of the disabled people's movement. Secondly, I explore the importance of incorporating independent living into law and policy, and the difficulties that may exist in ensuring that its oppositional purpose remains intact in these contexts.

Independent living was born out of resistance and its history has been well-documented by disabled activists.⁷ The term 'independent living' was coined in the USA by disabled student activists protesting against their exclusion from mainstream university life as a result of an inaccessible campus and imposed hospitalisation.⁸ In the UK, independent living originated in small groups of disabled people who sought to live outside institutions and secure support in daily living under their own control.⁹ Among the most well-known were those living in the Le Court residential home in Hampshire, who worked together to negotiate new support arrangements with the local authorities funding their placements at the home, finally moving into their own flats or houses in their chosen local communities. A crucial achievement of this group was the negotiation of cash packages from their local authorities in lieu of support, which enabled each person to employ personal assistants to provide daily living support under their own control. These were the forerunners of what are now called 'direct payments' in the UK, and in the UK context both direct payments and the use of personal assistance have historically been seen as critical enablers of independent living.¹⁰

Independent living was swiftly adopted by the UK disabled people's movement as a central aim.¹¹ Similar movements were developing elsewhere, particularly in the USA and the Nordic states. In 1989, disabled people founded the European Network on Independent Living (ENIL) and claimed independent living as an expression of rights.¹² Independent living has developed into a core demand of disabled people's activism across Europe and North America,¹³ and is increasingly becoming a campaign aim worldwide.¹⁴ It is now enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD), particularly Article 19. This provision sets out the

human right of disabled people to community living, with full inclusion and participation, and choices equal to others. It requires states parties to the CRPD to ensure that disabled people have choice in their living arrangements, individualised support to enable community living, and equal access to universal services and facilities.

In this article, I analyse documents from the UK disabled people's movement to explore how independent living functions as a counter-narrative to majoritarian social constructions of disabled people. In line with the UK disabled people's movement itself, I use the term 'disabled people's movement' to describe the informal network of activists who are themselves disabled, and organisations which are controlled by disabled people ('disabled people's organisations'). I also use the term 'disabled people', which reflects the social model of disability and is preferred within the UK disabled people's movement. I examine how independent living has been constructed to re-draw identities in such a way that disabled people can demand their rightful place in society on an equal basis with others. First I consider how the development of counter-narratives has historically been fundamental to the UK disabled people's movement. I then explore how independent living was conceptualised in the documents, how it performs the work of identity reconstruction, and complexities that arise within it, particularly the tension between the individual and the collective. Finally, I consider whether independent living can be accurately translated into law and policy.

2. Counter-Narratives and the Disabled People's Movement

The use of counter-narratives (or 'counter-stories') as an analytical tool originated predominantly in critical race theory, as a means of studying the minority ethnic experience.¹⁵ It has since been adopted by scholars exploring how socially marginalised individuals and groups use narratives to make sense of their experiences and lives.¹⁶ Counter-narratives are stories that challenge 'master narratives', or dominant accounts that circulate within society and delineate what are acceptable, 'natural' and 'normal' social behaviours.¹⁷ Master narratives develop our shared knowledge of what is 'right', but while they present as accepted fact, they are not neutral. They contain and perpetuate values that favour certain social groups while marginalising others, ascribing 'rightness' to the norms of the dominant group and failure and deficiency to those who deviate.¹⁸ Accordingly, they craft 'sub- or abnormal' identities for those in marginalised social groups, which justify their exclusion from identity-constituting roles and relationships.¹⁹

Counter-narratives challenge and resist these social 'norms'. They operate in different ways and at different levels. Some may exist as unconscious challenge when an individual finds that their experience does not 'fit' with societal expectations.²⁰ Others are intentional acts of personal or collective defiance against social stories which are recognised as oppressive.²¹ In all cases, counter-narratives demonstrate to the self and others that there are different possibilities to those which are socially ascribed, and demonstrate new ways of being. By asserting their own experience, the

individual or ‘outgroup’ engages in an act of narrative reconstruction through which their identity is reclaimed and their agency redeveloped and empowered.²² A particular role of a counter-narrative is to repair the internalised damage that occurs when individuals absorb and accept the identities ascribed to them, undermining their agency from within.²³ Counter-narratives construct a ‘repaired’ identity that commands respect for the outgroup and frees the individuals within it from narrative damage, enabling them to demand and take their just place in society.²⁴

Counter-narratives may be used by marginalised groups to (re)construct their identity and agency on a wider scale than the personal, and demand specific social changes.²⁵ In certain cases, change is sought at the level of law or policy.²⁶ Law and policy strongly influence social narratives and the construction of social identities, and are inherently connected to the material opportunities available to different social groups.²⁷ Accordingly, the successful insertion of a counter-narrative can facilitate powerful structural and cultural change, generating emancipatory possibilities for the outgroup. In the context of disability, the construction of disabled people as rights-holders rather than objects of charity paved the way for the development of anti-discrimination legislation. Similarly, the direct action campaigns of disabled people in the 1990s not only highlighted the deficiencies of inaccessible public transport and the need for policy and practical change, but also challenged perceptions of disabled people as passive and weak – including among the activists themselves.²⁸

While campaigning for policy change inevitably requires some form of contestation, such challenge will not necessarily operate as a counter-narrative. Indeed, the UK disabled people’s movement has historically criticised certain campaigns for actively reinforcing narratives of disabled people as weak and needy, or as social ‘others’.²⁹ In contrast, the movement itself was explicitly founded on resistance in the form of challenge to dominant social ideas. While campaigning organisations of disabled people have existed in the UK for at least a century,³⁰ the origin of the movement is generally considered to be the founding of the Union of the Physically Disabled Against Segregation (UPIAS).³¹ What differentiated UPIAS from previous organisations of disabled activists was their conscious and intentional challenge not only to the treatment of disabled people, but to the social construction of disability and narratives of the disabled identity. In 1975, UPIAS argued that:

[I]t 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.³²

This statement paved the way for Oliver’s development of the social model of disability. Oliver argued that disability was typically considered to exist within individuals, in the form of physical, cognitive or psychosocial variations in functioning characterised as deficits necessitating medical treatment or ‘correction’ to meet the standards of a non-disabled norm.³³ Oliver termed this the ‘medical’ or ‘individual’ model of disability. In response, and as an act of conscious opposition,³⁴ Oliver submitted that the source of disability was a *societal* failure to accept and accommodate different

experiences within the human condition.³⁵ A critical feature of this latter ‘social model’ of disability is the transference of narratives of deficit from the individual to society. Disabled people identified that social narratives of deficit had created specific social identities for them, ascribing certain roles and behaviours which had become socially entrenched and enabled their marginalisation. They challenged these by constructing a new narrative ‘located within the experiences of disabled people themselves’ which intentionally connected disability with oppression.³⁶

From its inception, therefore, the social model has functioned as a counter-narrative, or an ‘oppositional device’, that rejects existing ideas, enables disabled people to see each other as members of the same struggle, and produced ‘a new “we”’, with demands that required action by society rather than individuals.³⁷ The model has been subject to extensive analysis and debate within and beyond the movement, and both its purpose and value remain contested.³⁸ Even its most prominent critics, however, acknowledge the boldness of the model and its ability to challenge established ideas; and there is broad agreement that in the UK it created the basis for collective action constructed on a narrative of oppression rather than loss, enabling disabled people to advocate in the language of social justice instead of need.³⁹ The model also operates as a powerful means of identity repair, including the countering of internalised damage. As one disabled activist stated:

My life has two phases: before the social model of disability, and after it. ... 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.⁴⁰

Independent living builds upon the social model to become a second, complementary counter-narrative. Like the social model, independent living was a form of resistance. Unlike the social model, it grew as a *practice* rather than a theoretical standpoint, although activists also explored its theoretical implications. In 1986, Brisenden argued that certain ‘myths of disability’ had become entrenched as ‘facts’, creating a ‘mythologised physical norm’ against which disabled people were measured and inevitably held wanting. He argued that disabled people needed to create their own social narrative, built on the social model, to challenge and resist these ideas:

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.⁴¹

Brisenden concluded with a forceful depiction of independent living framed as a narrative working with and alongside the social model to challenge these dominant social accounts and the external and internalised damage they caused.

3. Methods

The purpose of this study was to examine how independent living conducted this work of resistance in texts authored by disabled activists in the UK. As there were no transferrable methods in the literature exploring counter-narratives, I drew on critical

discourse analysis to develop a study structure. Critical discourse analysis has much in common with the analysis of counter-narratives. It examines how language constructs identities and (re-)produces power and social inequalities. In critical discourse analysis the term ‘discourse’ refers to ways in which we talk about and understand the world,⁴² and particular discourses are considered to accord certain ideas the status of ‘common sense’ or ‘fact’ that create and perpetuate power structures and hegemonic social norms.⁴³ Critical discourse analysis is a theoretical standpoint, and methods used within it range from purely qualitative investigation, to combined qualitative and quantitative approaches. I drew particular inspiration from studies using coding as a means of identifying and exploring ideas in data to develop a study-specific method that combined rigour with qualitative analysis.⁴⁴

I selected a number of texts emerging from the UK disabled people’s movement, from its origins to the date of the study. To avoid ‘cherry picking’ data,⁴⁵ I developed selection criteria to ensure that texts were representative of the broad output of the movement, insofar as that was possible. A fundamental criterion was that documents must be authored by UK-based disabled people’s organisations or disabled activists who identified some form of connection with the disabled people’s movement. No more than three texts by any single author were included and, as far as possible, the selected documents were evenly spread across the full time-span of the movement to the date of the study. I sought to capture different ideas and forms of discussion by including texts from a broad range of document types, ranging from the personal to the formal, and works by both activist and ‘theorist’ authors, although these groups overlapped. The final dataset comprised 37 documents dating from 1966 to 2015, including speeches, seminar presentations, lectures, manifestos and other campaign materials, responses to policy consultations, reports on research, chapters of books and academic papers. A list of the dataset texts is provided in Annex 1.

As the study examined how independent living challenged socially dominant narratives around disabled people, I sourced the dataset documents (other than academic papers) from the public domain. All the documents could therefore theoretically contribute to the ongoing discussion about the place of disabled people in society. To obtain a range of documents, I searched disabled people’s organisations and think tank websites, academic journals, and personal blogs for potential data. Sources for earlier documents were more limited, and all the non-academic texts authored before 2001 were obtained from the University of Leeds Disability Archive.⁴⁶ As all the texts were publicly available, ethical approval for the study was not required. However, I approached the texts with the respect due to authors exploring forms of exclusion, marginalisation and oppression that were outside my lived experience and often deeply personal.

After reading the texts in detail multiple times, and making free notes on their content, I imported them into NVivo and identified all references to ‘independent living’. I coded all the extracts explicitly using this phrase according to the themes they contained, with all the codes arising inductively. Multiple themes emerged, including ideas related to identity, agency and personal outcomes, how independent

living could be enabled, the language of independent living, historical aspects, and threats to independent living. The themes selected for analysis related specifically to the identity and agency of disabled people and the personal outcomes envisaged by the authors. The key focus was on the content and expression of the themes and the relationship between them, rather than the number of times each theme was referenced, although this was noted. I examined the substance of the various themes, how they performed the work of narrative repair, and how they related to and dislodged master narratives. As with all methods, those used had certain constraints. The most significant was the restriction of detailed analysis to small sections of text, although this was offset by referring back to the broader documents during the analysis, to capture information about the themes that was present beyond these extracts.

4. Independent Living as a Counter-Narrative

Authors of the dataset texts, particularly the earlier documents, identified various dominant social accounts around disability, of which the most frequently mentioned was the medical model. The connected narrative of ‘personal tragedy’ was also explored.⁴⁷ Both articulate the idea of deficit, and other expressions of deficiency were also noted. Hunt,⁴⁸ Brisenden,⁴⁹ Sutherland⁵⁰ and UPIAS⁵¹ identified characterisations of disabled people as helpless, stupid, weak, pathetic, passive, incapable of decision-making, moral failures, useless and inadequate. These narratives were felt keenly by these authors, who used the language of waste, inferiority and sub-humanity to describe either the construction of disabled people or disabled people’s resulting experiences. Narratives of otherness were also identified. Hunt described disabled people being constructed as ‘others’, as ‘deviant’, ‘different’ or ‘unlike the normal’ and – in language that also reflected defect – ‘only half alive, only half human’.⁵² Brisenden considered disabled people to be portrayed as a ‘different and unfortunate species of being’.⁵³

Master narratives of dependency were also identified, although the texts demonstrated a complex relationship with this idea. Dependence was seen as both an oppressive narrative, connected with ideas of incapacity, charity and paternalism,⁵⁴ and a demeaning externally imposed experience for disabled people that arose from attitudes and policy built upon these narratives.⁵⁵ However, it was also viewed as a natural and acceptable part of disabled people’s lives – in that many disabled people need support in daily living⁵⁶ – and as a fundamental element of the *universal* human condition. *Interdependency*, or the reliance of all people on others for fulfilment of their physical and social needs, was explored.⁵⁷ However, certain ideas seen as connected to dependency, including charity, paternalism and ‘care’, were emphatically rejected. The essential function of all these narratives was considered to be the servicing of the needs of socially dominant groups, with non-disabled people benefitting from the reassurance of their ‘normality’ and superiority, and the othering of those who represent susceptibility to illness and mortality.⁵⁸

Independent living repudiated the identified master narratives in multiple ways, constructing wholly new identities and new forms of agency for disabled people. The core themes connected to independent living in the dataset fell into three broad ‘clusters’ of ideas, in which certain conceptually related themes tended to appear together in the same extracts of text. The first related to the idea of self-determination, the second to social inclusion and the third to equality and rights. These groups were not discrete or precisely delineated – themes from each might be found in the same extracts – but remained distinctive. Each cluster formed a ‘sub-narrative’ of the broader counter-narrative that was intertwined with both the others to construct a ‘repaired’ disabled identity. I conceptualise them here as ‘personal agency’, ‘social agency’ and ‘citizenship’.

Each of these sub-narratives played a particular role in refuting and resisting the master narratives of defect, deficit, otherness and inferiority that were collectively identified in the dataset documents. It was clear that all three had arisen in response to the institutionalisation experienced by many of the authors, which remained part of the collective knowledge of the movement and an ongoing threat. Essentially, personal agency challenged the denial of self-determination that the authors had experienced through ‘batch’ living;⁵⁹ social agency confronted the extreme form of social exclusion generated by the physical removal of disabled people from society, and citizenship generated an argument of social justice. Each sub-narrative also contained more subtle elements of identity repair, as outlined below.

4.1. Personal Agency

The predominant themes within the sub-narrative of personal agency were those of choice and control. These were among the most frequently and consistently referenced themes and were also present and emphasised in texts that pre-dated the rise of independent living. Both were expressed as unlimited and uncompromised ideas – phrases such as ‘more control’ were almost entirely avoided, and choice was presented as full choice by the individual rather than the selection of options presented by external parties. Of these two ideas, control was prioritised, appearing more often and sometimes strongly emphasised, particularly in early texts. For example:

[I]ndependent living pivots on the right to control our lives ... CONTROL is the central component of independent living.⁶⁰

These ideas were very closely connected, appearing in the same extracts and reinforced through repeated use of the phrase ‘choice and control’. In the dataset texts this was first connected to independent living in 1992 and featured in the extracts consistently from 2004, almost as a ‘slogan’ for independent living. In 2001, Evans described choice and control as the ‘fundamental principles’ of independent living,⁶¹ and ten years later, Morris identified them as the *definitional* themes:

“[C]hoice and control” ... was and is the phrase used by the disabled people’s movement to define independent living.⁶²

The relationship between choice and control was not explored in the extracts but, broadly speaking, choice expressed the possibility of life opportunities unrestricted by inadequate access or assistance, and control the need to be free from externally imposed decisions. From the earliest stages both were specifically connected to support:

The particular issue which ... is most closely associated with [independent living], is that of control over the Personal Assistants required to overcome individual physical and/or intellectual limitations.⁶³

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.⁶⁴

Both were also connected to equality and rights:

... 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.⁶⁵

As these latter quotes demonstrate, a fundamental aspect of the personal agency sub-narrative was its relation to the individual. This connection was explicit and intentionally established the primacy of a narrative of *self*-determination. But despite this strong focus on individualism, the extracts also emphasised the existence of a collective and community identity. There were multiple references to 'our lives', 'us' and 'we', expressing solidarity and connection; and certain authors, particularly Morris⁶⁶ and Zarb,⁶⁷ emphasised the need to ensure that independent living included people with cognitive or communication impairments. There was also explicit consideration of the interconnection between the personal and the collective identity:

[E]ach 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 ... demands the exercise of responsibility and citizenship. True equal opportunity, enabling the exercise of personal attributes in furtherance of personal responsibility and collective dependence.⁶⁸

This solidarity was emphasised by references to peer support and the development of centres for independent living, through which disabled people assisted others to live self-determined lives in the community. Both these collective mechanisms were considered fundamental to enabling individual independent living from the earliest days.⁶⁹ However, the individualism of personal agency was strong, and emphasised in certain texts by the positioning of direct payments and personal assistance as fundamental enablers of independent living.⁷⁰ Personal assistance, funded by direct payments, was typically positioned as the key means of translating the individual's ability to know their will into the ability to enact it, and both mechanisms were strongly linked with self-determination:

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.⁷¹

The narrative of personal agency directly disputed the construction of disabled people as lacking the capacity to reason, to hold views, and to self-determine. It demonstrated that the lack of choice and control experienced by disabled people was externally imposed, not a failure of will or competence on the part of individuals. The texts were also an expression of personal agency, evidencing disabled people's individual and collective capacity to debate and theorise, refuting constructions of disabled people as 'others'. Like the physical direct action protests by disabled people mentioned above, the texts and the practice of independent living demonstrated as well as demanded power. For disabled people, immersed in narratives of passivity and deficit and expected to fulfil social roles as dependents and recipients, these statements of personal agency created radical new ways to envisage themselves as authoritative individuals.

4.2. Social Agency

The sub-narrative of social agency contained themes connected to inclusion and everyday activity. They included living in the community, inclusion, participation, having one's own home, and living a fulfilled life, including through employment and education. Of these themes, community or non-institutional living was positioned as an absolute requirement. Independent living was consistently set out as the 'antithesis' of institutional living,⁷² with the latter equated to incarceration,⁷³ imprisonment⁷⁴ and ghettoisation.⁷⁵ When discussing institutionalisation, authors strongly conveyed the negation of personal agency and even humanity.

... 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 minimum services necessary for day to day survival.⁷⁶

The themes of inclusion and participation in society, and an active, meaningful life were very closely intertwined, repeatedly appearing in the same extracts. They were also strongly connected to equality. Like choice and control, inclusion and participation were presented as full, uncompromised ideas, with phrases such as 'full inclusion' frequently used.

As well as the themes of employment, education and the need for a meaningful, fulfilled life, the extracts containing themes relating to social agency were rich in ideas concerning the quality of life and people's humanity, including individual personality and personal development,⁷⁷ personal relationships⁷⁸ and sexuality.⁷⁹

Many extracts that conveyed the narrative of social agency also contained a strong sense of personal agency, indicating that the engagement of disabled people in community life should be on their own terms to enable the life of one's own choice.

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.⁸⁰

The essential purpose of the narrative of social agency was to construct disabled people – individually and collectively – as capable and competent actors with the desire and right to engage in social activities on the same basis as others and as an *integral* part of the wider community. Social agency constructed disabled people as natural social participants, and their marginalisation as an artificial human state. Social agency thus performed critical narrative repair by resisting the ‘othered’ identity in which disabled people had been constructed as inadequate, defective and inferior. The typical social roles and identities created for disabled people in the texts, together with the discussion of family relationships and universally experienced aspects of the human condition, created a disabled identity based on sameness rather than difference. Social agency also retained a profound sense of the self. By connecting social agency to personal agency, the texts indicated that the engagement of individuals in society should be on their *own* terms, creating a community identity with individual integrity as a central element. Overall, the narrative of social agency enabled disabled people to think of themselves not as social ‘waste’, but as family members, parents, workers and participants engaging with the world as valued individuals within society. Working both alone, and with personal agency, it generated a narrative of entitlement and human value.

4.3. Citizenship

The narratives of personal and social agency were suffused with the themes of equality and rights. As indicated in the above extract, equality was connected with social activities (‘use the same bus as our neighbours’) and personal agency (‘the same choices and control’). Equality was demanded in terms of equal opportunities,⁸¹ equal social access,⁸² equal worth,⁸³ equal citizenship⁸⁴ and equal rights.⁸⁵ It was also articulated as a common and pre-existing human *state* – that disabled people *were* the same as those without impairments, with shared human experiences, ambitions and desires.

That is the fascination of independent living. Disabled people are no different to anybody else. We develop as people socially, economically, politically and philosophically.⁸⁶

The theme of rights was connected to independent living both within and well beyond the sub-narratives of personal and social agency. Numerically, rights was the most frequently referenced theme in the extracts other than threats to independent living. From an early stage, independent living was emphatically expressed as a right in itself:

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.⁸⁷

Independent living was also constructed as the means by which disabled people would access their broader human rights; *and* as the expression of these rights.

Without Independent Living we do not have our Human Rights and without Human Rights we do not have Independent Living.⁸⁸

Equality and rights were also discussed extensively in the wider documents, and were pivotal demands in many texts. Notably, identifying disabled people as rights-holders rather than objects of care and management was considered another core means to shift dominant social narratives – and the third ‘big idea’ of the disabled people’s movement.⁸⁹

The strong connection of independent living to equality and rights framed it as a matter of social justice. Equality and rights carry legal connotations, both as positive obligations and as indicators of discrimination. The construction of independent living as a right enabled disabled people to reconfigure their identities as *natural* rights-holders rather than welfare or charity beneficiaries, and develop a status based not on their disabled identity, but on their common existence as citizens on an equal social and legal footing as their non-disabled peers. The construction of independent living as a right in itself, and inseparably connected to universal human rights, also elevated it to a different legal level. The denial of such rights is a profound form of oppression which is not only morally objectionable, but capable of triggering legal complaint. These themes therefore achieved both the feat of narrative repair, raising the social status of disabled people and countering master narratives of deficiency, otherness, care and charity, and opened up avenues to demand the creation of actionable legal duties.

5. Independence, Individualism and the Self

The importance of individualism and the self in the independent living counter-narrative is indicated above. This focus was fundamental and pervasive. It appeared not as a consciously selected idea but an inherent element of the narrative repair, and a necessary component of the rebellion against the externally imposed control that disabled people had experienced through institutional living and the influence of others over their lives. It was also practically necessary. In a non-dataset text three of the Le Court pioneers described how they originally intended to share a house but ultimately chose to live apart as their expectations, ambitions and lifestyles differed.⁹⁰ This focus on the self pulled against the collectivism that has historically been fundamental to the disabled people’s movement. UPIAS was formed as a *union* of disabled people, founded on principles of solidarity, and the social model of disability was intentionally developed to refute narratives of disability that Oliver had identified as arising from an ‘ideology of individualism’.⁹¹ Both UPIAS and Oliver drew on Marxist approaches in their analysis, and the social model is characterised by values of communitarianism. It demonstrates the collective, societal change necessary for disabled people to take their rightful social place. The fundamental focus on the self within independent living therefore created a paradox, in which the individual is refuted as a *cause* of disability while individuality in *responses* had traction.

The focus on the self, however, enabled independent living to provide a personal counterpoint to the collective focus of the social model. Certain dataset texts referred to the close connection between independent living and the social model, conceptualising this connection in different ways. Zarb submitted that independent

living ‘mirrors the essential principles of the social model’,⁹² Beresford that it ‘follows from’ it,⁹³ and Morris that the social model underpinned it.⁹⁴ Finkelstein pictured independent living as a *component* of the social model.⁹⁵ In the texts, independent living was connected explicitly and implicitly to access, and it was clear that it depended in part on the removal of environmental, organisational and attitudinal barriers that the social model demands. Similarly, both independent living and the social model demanded full and equal social inclusion, framing exclusion as a societal response to impairment. There were, however, distinctions. Morris stated that definitions of independent living generally contain three components:

*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.*⁹⁶

When compared with the principles of the social model, the distinctive features of independent living are the explicit and central emphasis on personal agency, the (connected) focus on individual control over support, and the introduction of the concept of independence in a specific format. Each of these emphasises individualism – independence itself is a concept that deals with relationships between the self and others. Independent living thus essentially built upon the social model to create a more detailed understanding of what is required for individual disabled people to live their own lives. Within the social model, individual liberation and self-determination are achieved through the communitarian solutions of access and integration. Independent living focuses on the individual and works outwards. Its existence – and its development as a lived rather than a theoretical position – suggests that something beyond the social model was needed to counter the denial of personal identity experienced through institutionalism and ‘batch-living’, and remains necessary to enable disabled people to construct themselves in the light of their own, as well as their collective, desires and experiences. Both, however, contest the master narratives that enable damaging social constructions of disabled people and their societal position. They operate as complementary counter-narratives, working separately and together to reconstruct disabled people as social individuals with a right to live their own lives as equal citizens.

Given the increasing understanding of our multiple social identities and their combined intersectional impact, the individualism celebrated in independent living may be fundamental to anybody seeking to choose, define and assert their own ways of being against dominant social narratives. The focus on individualism is likely also to be of great importance to disabled people who remain subjected to unequal social choices, inadequate assistance and the threat or reality of institutional living. Conversely, the focus on the individual has the propensity to fragment the collective activity that is fundamental for a social movement to remain effective and for counter-narratives to be further explored, refined and developed. The creation of counter-narratives capable of changing external behaviours is *necessarily* a group activity, requiring group discussion and collective validation of new social narratives.⁹⁷ As

a counter-narrative, therefore, independent living is finely balanced between enabling the individual expression vital for disabled people to reconstruct their personal social identity, and undermining their shared experience and the solidarity and collective functioning of the movement.

A risk in this context is the possibility of particular forms of independent living emerging as a result of interaction with specific socio-political environments. In dataset texts, the authors Finkelstein, Davis and Shakespeare each expressed unease about the emphasis on independence within independent living and the overtones of individualism that it conveys.⁹⁸ Davis and Finkelstein voiced particular concerns that direct payments were based on individualised consumer ideals that might undermine the movement's collectivist principles and threaten its fragmentation, particularly in the context of welfare state residualisation and marketisation that has existed in the UK since the 1980s. UK public sector policy has indeed been driven by a neoliberal agenda of personal responsabilisation, privatisation and fragmentation for decades, and direct payments construct disabled people as consumers and administrators of public funds in a way that has potential value to this ideology. It is also the case that this coincidental confluence was consciously deployed by the disabled people's movement. In one of the dataset documents, Morris stated that during the campaign to place direct payments on a legal footing, the movement 'use[d] language which fitted well with the individualist political framework which was becoming more and more dominant', and that this might have unintentionally 'contributed towards a steady undermining of collective responsibility and redistribution'.⁹⁹ While the development of legislation on direct payments was a triumph for independent living campaigners, it is notable that enablers of independent living that speak to the movement's collectivism – such as peer support through disabled people's organisations – have not been formalised in policy and law and are increasingly under threat.¹⁰⁰ It is therefore possible that in the UK context a particular form of independent living has come to the fore as a result of interaction with the local political agenda.

6. Incorporation into Law and Policy: Recognising the Challenges

I state above that one role of counter-narratives may be the reformulation of identity at a structural level, including by their incorporation into law and policy. Such incorporation has the potential to engender social structures that are emancipatory for the excluded social group by dislodging master narratives and re-drawing social identities at a fundamental level. As independent living develops as a campaign aim of disabled people's movements globally, it is increasingly likely that attempts will be made to insert independent living into national policy and legislation. In the UK, such attempts have had some success. In the mid-2000s the (then) UK government worked closely with disabled people on policy initiatives constructed expressly around independent living.¹⁰¹ Both this level of joint working and the detailed focus on independent living have since waned at the level of central government, although

independent living continues to be a purported guiding principle of UK disability policy,¹⁰² and is strongly visible in policymaking in the devolved UK nations.¹⁰³ While attempts to introduce a statutory right to independent living have been unsuccessful in the UK, guidance under both the Care Act 2014 and the Social Services and Well-being (Wales) Act 2014 states that the wellbeing duties introduced by these statutes are intended to include key elements of independent living.¹⁰⁴

Despite these successes, independent living has not yet become a consistent reality for disabled people in the UK. Indeed, discussion on independent living within the disabled people's movement has recently focused on retrogression rather than success.¹⁰⁵ Research by disabled activists and others demonstrates that the implementation of the 2014 statutes has failed to ensure that independent living is a reality for those who need assistance in everyday life partly, but not entirely, due to the impact of austerity on local authority budgets.¹⁰⁶ Other policy initiatives, particularly in relation to housing, welfare and employment, have had such a significant impact on disabled people that the UN Committee on the Rights of Persons with Disabilities has declared the outcome a 'human catastrophe',¹⁰⁷ and disabled activists have described independent living as being 'systematically dismantled'.¹⁰⁸ There is therefore an obvious disjunct between the stated incorporation of independent living into national policy and the lived experience of disabled people. Implementation is clearly part of the problem, but questions also arise as to both the accuracy of the construction of independent living in the policy and legal context and the *purpose* of its inclusion. Beckett and Campbell have argued that the social model has been co-opted by the UK government to service a neoliberal agenda,¹⁰⁹ and certain dataset texts expressed fears about a similar fate for independent living.¹¹⁰ Indeed, Morris explored how independent living, and other ideas emanating from the disabled people's movement have been systematically 'colonised and corrupted' to drive policies that actively disadvantage disabled people.¹¹¹

Further exploration of the possible co-optation of independent living is certainly required. In addition, I suggest that a further problem may relate to the attempted or perceived inclusion of independent living in governmental disability strategy, alongside the *accidental* omission of its fundamental content. In Wales, the Welsh Government's disability strategy (at the time of writing) is the stated vehicle for implementing independent living.¹¹² It comprises multiple separate policy initiatives, each of which *may* contribute to the realisation of independent living outcomes, but these are attached to the concept of independent living rather than flowing from independent living as an animating principle. Consequently, independent living is reduced to something of a policy by-product, and challenge to socially dominant narratives of disability is limited, despite strong discussion of the social model.¹¹³ The document suggests that independent living can only be *effectively* incorporated into policy and law if there is shared recognition among all stakeholders of the narrative repair that independent living performs, *and* a shared intention to ensure that the policy or legislative product intentionally reproduces this repair. I submit that the presence of the themes of the counter-narrative in policy and law

without the reproduction of this central element risks fragmenting the counter-narrative and lessening its impact. Indeed, the incorporation of partial or imperfect elements of independent living allows policy to give the appearance of supporting independent living without challenging master narratives that continue to restrict the identities and agency of disabled people. In this eventuality these master narratives are likely to be reinforced and the radical potential of independent living neutralised. If independent living is to work as an effective counter-narrative in policy, and fulfil its role in reconceptualising disabled people's identities and agency, it must be seen not *just* as the realisation of certain material outcomes but consciously and consistently viewed as an intentional challenge to the dominant social norms that continue to negate social justice for disabled people.

The CRPD is a key tool in countering this difficulty. In the UK disabled activists have used the Convention to resist retrogression in their human rights, including the right to independent living.¹¹⁴ Notably, the CRPD *itself* functions as a counter-narrative. One of its core purposes is to challenge existing narratives of disability and shift thinking around disabled identities. Quinn and Doyle state that the CRPD 'effectuates a paradigm shift in the context of disability', framing disabled people as rights-holders and equal citizens rather than objects of care or charity.¹¹⁵ Article 19 is a critical provision in the Convention contributing to this shift. It views disabled people as autonomous beings living fully integrated lives with opportunities equal to others,¹¹⁶ and the 'choice, freedom, and inclusion' it demands are 'considered prerequisites for exercising all other [Convention] rights'.¹¹⁷

Unsurprisingly, Article 19 has become a focal point of UK activists seeking to realise independent living and to embed it in policy.¹¹⁸ This focus is also seen *beyond* the disabled people's movement. For example, Article 19 is explicitly referenced in the Welsh Government's strategy on independent living discussed above; and in 2012 the UK Parliament's Joint Committee on Human Rights reported on the implementation of the rights of disabled people to independent living, 'as enshrined in Article 19'.¹¹⁹ However, the focus on Article 19 alone risks overlooking other CRPD provisions that are fundamental to the equality and social opportunities envisaged within independent living. The right to full autonomy and an equal life expressed in Article 19 is bolstered and complemented in other provisions of the Convention. Article 12 recognises that disabled people have legal capacity that is equal to others regardless of their cognitive ability. Article 1 references the social model of disability, Article 8 requires challenges to existing perceptions of disabled people, and Article 3 establishes 'individual autonomy including the freedom to make one's own choices, and independence of persons' among the core general principles of the Convention. Other provisions address matters such as accessibility (Article 9), employment (Article 27), family life (Article 23), and participation in political, public and cultural life, and in recreation, leisure and sport (Articles 29 and 30).

In other words, it is the Convention *as a whole*, rather than Article 19 alone, that speaks to independent living. Accordingly, a conscious focus on the full content of the CRPD would facilitate the incorporation of more accurate renditions of independent

living in policy or law, if only because this more comprehensive approach may more effectively dispel damaging master narratives. In the legal or policy context, counter-narratives may dislodge master narratives in one (or both) of two ways – either through intentional incorporation of the central purpose of resistance and the deliberate and consistent re-drawing of social identities, or by the incorporation of sufficient elements of the counter-narrative so effectively that existing dominant accounts are lessened and ultimately overwhelmed. A holistic focus on the Convention on the Rights of Persons with Disabilities, and a shared understanding among policymakers of its status as a document of resistance, is of value in either context, and has the potential to bolster independent living against both intentional and accidental co-optation.

As global activism around independent living continues, disabled activists are increasingly likely to seek its incorporation into law and policy. Evidence from the UK suggests that the *accurate* translation of independent living into law and policy is fundamental for its emancipatory potential to be released, but that this is challenging for many reasons. More work is needed by both disabled activists and academics to better understand the interaction between independent living and social policy. We need to know whether law and policy that are *said* to enable and support independent living are *actually* performing these functions, and, if not, whether these difficulties relate to implementation or to how independent living is conceptualised in the relevant law and policy contexts. Equally important is knowledge as to how independent living can retain its focus on the individual while also embracing the collectivism that is fundamental to disabled people's movements globally, and how forms of independent living can be forged which are appropriate to different cultures and environments without being unduly influenced by potentially damaging external agendas. If independent living is to fulfil its role in enabling equality and social justice for disabled people, we need to understand how it is constructed in law and policy, and examine whether this construction accurately re-draws the identity and agency of disabled people in such a way as to enable their full emancipation.

7. Conclusion

Independent living is increasing in importance as a demand of disabled people's movements across the globe. In this article I have introduced the theoretical device of a counter-narrative to explore independent living as it has been created by disabled activists in the UK. I suggest that independent living complements the social model of disability to ensure that the 'we' of the disabled people's movement is able to retain a focus on the 'I' of the individual; and highlight the work of resistance and identity reconstruction that independent living performs. I argue that a fundamental aspect of independent living is its creation of 'repaired' social identities for disabled people which resist dominant narratives of otherness, deficiency and dependency and liberate disabled people's agency. I submit that the incorporation of independent living into law and policy is a powerful means by which its emancipatory potential may be realised, but that where such incorporation is attempted it is vital that the resulting product retains the element of identity repair. If the content

and purpose of independent living are to be fully realised, its existence as a challenge and a form of narrative reconstruction must be expressly understood, and this element consciously placed at the heart of policy and legislation.

Annex I: The texts in the dataset

Documents are listed in date order. A list of abbreviations is provided below.

Paul Hunt, 'A Critical Condition' in Paul Hunt (ed), *Stigma: The Experience of Disability* (Geoffrey Chapman 1966).

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- 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'.

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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*

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