Introduction

Action on Disability: The Right to Independent Living (‘Action on Disability’) is the Welsh Government’s successor document to the Framework for Action on Independent Living (2013). A consultation document was published on 22 October 2018. This article sets out the content of the consultation document and considers a number of issues that it raises.

The document is in two sections: a ‘Framework’, which is intended to set out the context and commitments of the Welsh Government; and an ‘Action Plan’, which outlines current actions and will be updated. It is stated that good practice examples and case studies, FAQs, a glossary of key terms and accessible versions of the Framework will also be provided. As with the 2013 Framework, while Action on Disability is focused on independent living, it is also stated to be the means by which the Welsh Government will fulfil its obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

Overall, it has to be said that Action on Disability, in its current form, is disappointing. This was an opportunity for the Welsh Government to develop a powerful overarching strategy on the rights of disabled people, developing and building upon ideas that were initially set out in the 2013 Framework and committing itself and others to a number of actions that would enable independent living to flourish and evolve in the Welsh context. Instead, it contains significantly less content than the original Framework, is light on policy, and contains limited strategic vision.

The Welsh Government faces a number of challenges in supporting and implementing independent living. It has no control over certain critical matters, including the welfare system, and legislation in relation to equality, discrimination and mental capacity. It has been subject to a brutal austerity programme, imposed by the

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4 This article is informed by PhD research carried out by the author. It should be taken as an academic response to the consultation document and is by no means intended to indicate or be a substitute for the views of disabled people or disabled people’s organisations. I am supportive of the aims of Action on Disability, and wish to see independent living thrive in Wales. If discussion of any issues raised in this article would be of assistance, I can be contacted at TarrantAE2@cardiff.ac.uk.

5 How often this will be updated is not stated.

6 Page 6.
UK Government, which has had a particular impact on disabled people. The Welsh Government has also faced difficulties over the lifespan of the development of *Action on Disability*. It has been required to deal with the challenges and uncertainties of the Brexit process and its own internal stresses. However, there have also been opportunities. The Welsh Government has seen an increase in its competence in both legislative and financial terms, which will give it new powers to develop radical and distinctive policy on devolved matters.

**The general content of Action on Disability**

Independent living is generally interpreted as the right of disabled people to lead free and active lives as full members of the community, on an equal basis as others and with control over the support they need. It is a concept that was devised and developed by the disabled people’s movement as a challenge to ideas and policies that excluded and disadvantaged disabled people and which denied them the right and the opportunity to take part in society. The 2013 Framework reflected this heritage. It was constructed around a series of priorities identified by disabled people in Wales, and contained a number of principles and statements that echoed principles developed by disabled activists.

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8 *Action on Disability* initially fell within the portfolio of the Welsh Government Secretary for Communities and Children, a position then held by Carl Sargeant AM. The tragic death of Carl Sargeant in November 2017 sent shock waves through the Welsh Labour Party and led indirectly to the resignation of its leader and First Minister Carwyn Jones AM. At the time of writing Mark Drakeford AM had recently been announced as the successor to Carwyn Jones as Leader of Welsh Labour, and was expected shortly to assume the role of First Minister.

9 The Wales Act 2017 changes the devolution settlement in Wales from one of conferred powers (in which certain fields are devolved to the Welsh Government) to one of reserved powers (in which the Welsh Government has competence to act on any area save those ‘reserved’ to Westminster competence. The 2017 Act also expanded the fiscal powers of the Welsh Government including a level of control over income tax in Wales.

10 John Evans, one of the pioneers of independent living in the UK, describes independent living as: ‘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’. J. Evans, ‘Independent Living and Centres for Independent Living as an Alternative to Institutions’ (2001, unpublished) https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/evans-Centres-Independent-Living-Alternative-Institutions.pdf accessed 11 December 2018.


12 Chapter 4 of the 2013 Framework, which discussed the enablers of independent living, was split into six sections reflecting the priorities identified by Disability Wales through consultation with disabled people in Wales and set out in its 2010 Manifesto for Independent Living. These priorities were also reflected in Chapter 3 of the original Framework, which set out ‘Outcomes, Actions and Delivery Partners’. (The Disability Wales Manifesto for Independent Living is no longer available online).

13 One of the four ‘core values’ of independent living outlined in the original Framework was that of ‘choice and control’ – two values that have been consistently set out as core elements of independent living by the disabled people’s movement. See Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation, 2011).
Perhaps the most obvious distinction in the revised document is that this foregrounding of the priorities and expertise of disabled people has been removed. Action on Disability is explicitly stated to be as much about the priorities of the Welsh Government as those of disabled people; and is structured around the Welsh Government’s own priorities, as set out in its national strategy: Prosperity for All. From the outset therefore, there is a pronounced shift in emphasis away from the concerns of disabled people and towards those of the Welsh Government. In terms of independent living, this is a retrogressive step – it suggests that matters of importance to disabled people are no longer paramount in policy on independent living in Wales, and creates a risk that aspects that are less confluent with the Welsh Government’s own principles will be side-lined. Certain ideas, such as the development of centres of independent living and other disabled people’s organisations, which enable peer support for disabled people, already appear to have been lost.

Equally notable is the lack of strategic content in Action on Disability. If the first part, or ‘Framework’, is to stand as a relatively permanent document that sets out how the Welsh Government is fulfilling its obligations under the UNCRPD, as well as its policy priorities in relation to independent living and to disability more broadly, it must be robust, and establish a clear, consistent vision for long term action and solid aims. The consultation process to date has provided the Welsh Government with information on the issues faced by disabled people in Wales. What is lacking is a clear analysis of the underlying structural issues and statements as to how the Welsh Government intends systematically to address these issues, both through its own actions and through requirements placed on others.

The Framework contains four short chapters comprising the statutory and policy context, progress and developments since the 2013 document, issues raised by disabled people in consultation events, and the Welsh Government’s commitments. Of these, the first three chapters are almost wholly contextual and the fourth contains a number of statements that are currently too broad to be of practical or systemic use. There is no discussion of the challenges that face the Welsh Government and other bodies in enabling independent living and barrier removal, and how these can be overcome, and no discussion of the prioritisation of aims and resources in a difficult financial climate. Other than the definitions of independent living and the social model of disability in Chapter 1 (see further below), there is nothing in these chapters that moves towards an overarching national strategy that sets out a progressive vision for the realisation of independent living in Wales, or will require barriers to independent living to be consistently and methodically removed. No

16 Action on Disability notes that issues identified by disabled people and Welsh Government priorities may be ‘one and the same’ (page 6) but does not state what will happen where they are not.
17 It is odd that this chapter, which will presumably date as fast as the Action Plan, has been incorporated into the Framework, which will not be updated, rather than the Action Plan, which will. A more logical structure would be for this section to form the first section of the Action Plan.
18 Commitments include, for example: ‘The Welsh Government will work for continuous improvement in how Wales fulfils its obligations with regard to the UN Conventions on the Rights of Disabled People and the Rights of the Child’; and ‘The Welsh Government will work with partners to explore options for a new approach to encourage organisations to improve how they work with and support disabled people, including staff, customers and the general public’ (pages 28-29).
requirements are placed on external agencies – including state agencies that the Welsh Government has the power to direct – although there are statements to the effect that the Welsh Government ‘expects’ the Framework and Action plan to be supported by both state and other agencies.\(^{19}\)

Perhaps most frustratingly, the issues raised by disabled people, set out in Chapter 3, are not strategically or comprehensively addressed. While there is detail, this is not brought together into broader discussion. There is no examination, to take just one example, of the multiple reasons for the chronic poverty experienced by many disabled people and how this might be tackled. Shocking statements of inequality – such as differences of health outcomes including life expectancy\(^{20}\) and educational achievement\(^{21}\) – for disabled people are not explored. The only statements as to how the matters raised during the consultation will be dealt with are the disparate actions set out in the Action Plan.\(^{22}\) While these actions are welcome, they are not bound together by any underpinning rationale or coherent attempt to realise independent living or implement the UNCRPD. They read as a series of ongoing or planned actions which have a connection to issues raised by disabled people,\(^{23}\) rather than a reasoned statement of actions intentionally pointing towards a specific, stated set of outcomes or a series of progressive aims. However important they are, there is no indication of why these actions have been prioritised, what the expected outcomes are and what subsequent action will (or may) be required. No timescales or specific targets are given. It is also, at best, a partial approach to the UNCRPD. A number of Articles of the Convention are not mentioned, despite their relevance to the devolved context in Wales.\(^{24}\)

The definition of independent living and the social model of disability

The document provides a revised definition of independent living. Given the importance of this definition for the understanding of independent living in the Welsh context, it is given here in full. It reads:

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\text{Independent living means all disabled people having the same freedom, dignity, choice and control as other citizens at home, work, in education and in the community. It does not necessarily mean living by yourself or having to do everything for yourself. It means rights to practical assistance and support to participate fully in society on the same basis as others.}
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\(^{19}\) For example: ‘It is therefore Welsh Government’s clear expectation that all Welsh public service providers and many organisations and individuals in the private and third sectors will actively support this Framework and its accompanying Action Plan. In particular, we encourage others to adopt the commitments set out in Chapter 4 of the Framework and put them into practice in organisations, services and communities throughout Wales.’ (Page 9). It is of course the case that the existing legal and policy framework already creates various requirements, but these are not brought together to give a coherent sense of an overall approach towards prioritised solutions.

\(^{20}\) Page 22.

\(^{21}\) Page 24.

\(^{22}\) The Action Plan contains a variety of current and proposed actions ranging from high level objectives such as ‘Delivering the Employability Plan for Wales’ to more specific objectives such as installing lifts to provide access to the battlements of Caernarfon Castle.

\(^{23}\) For example, ‘Prosperous and Secure’, Point 11. ‘We will: Through the Innovative Housing Programme, stimulate new thinking in the design and delivery of affordable housing to reflect the overarching aims of the Well-being of Future Generations Act.’ (Action Plan, page 5).

\(^{24}\) There are, for example, no actions that are considered to contribute towards the realisation of Article 4, which imposes a number of general ‘implementation’ obligations upon states, or Article 26, which requires states to ‘organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services’. 
It is about ensuring people of all ages and from all communities are able to maintain independent living, enjoy well-being and access appropriate support when and how they need it.\(^{25}\)

The definition is clearer than that provided in the 2013 Framework and its clarity is welcome. It articulates the core essential elements of independent living as it is has been set out by the disabled people’s movement in the UK and in Wales: \(^{26}\) equality, self-determination and full participation in society ‘on the same basis as others’. Unlike the 2013 document, equality is emphasised and there is an explicit statement that independent living does not mean self-reliance or living alone – a matter that has frequently been misunderstood (see further below).\(^{27}\) There is also a clear (and repeated) statement that people have the right to assistance to enable equal participation. It is not precisely stated that disabled people should have choice and control over this support – another essential element of independent living as it is understood in the disabled people’s movement\(^{28}\) – although there are hints to this effect in the statement ‘when and how they need it’.

The statement of the obligations on the Welsh Government under the UNCRPD is, unfortunately, not similarly complete. \textit{Action on Disability} is described as a statement of ‘how the Welsh Government will be taking forward the principles of the Convention’.\(^{29}\) The explanation of Article 19, however, obscures the nature of the obligations on signatory states. Article 19 creates three specific obligations: that disabled people have the same opportunities as others to choose where and with whom they live, that disabled people have access to specific support to enable them to live and take part in the community; and that universal community services and facilities are equally accessible to disabled people. The statement given in the Framework, which outlines the broad general principle of Article 19, is not inaccurate, but provides a profoundly partial explanation of the duties on the Welsh Government.\(^{30}\) In addition, no other Articles or obligations under the UNCRPD are discussed in any detail.

\(^{25}\) Page 10, original emphasis.
\(^{26}\) Disability Wales provided an explanation of independent living in 2010. This states: ‘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.’ Disability Wales, ‘Manifesto for Independent Living’ (2010, unpublished), page 6.
\(^{27}\) See, for example, Jenny Morris, \textit{Rethinking Disability Policy} (Joseph Rowntree Foundation, 2011). In Wales, see Vin West for the Arfon Access Group, Letter to Sarah Beasley, Clerk to Health & Social Care Committee, National Assembly for Wales (15 March 2013). Whether this misunderstanding is unintentional or wilful is arguable either way. In the English context, Morris argues that this is an intentional co-optation and distortion of the language and ideas of the disabled people’s movement. There has been less consideration of similar points in the Welsh context.
\(^{29}\) Page 11. It should be noted here that the Welsh Government is obliged to do more than apply the principles of the UNCRPD. The UNCRPD is a legally binding treaty that all governments in the UK are required to implement. In relation to devolved matters, the UK government discharges its duties through the actions of the devolved governments.
\(^{30}\) The Article states that: ‘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
Independent living builds on the social model of disability. 31 As with the 2013 document, the new Framework places a particular and strong focus on this model. The extensive and detailed explanation of the social model is therefore a welcome addition to Action on Disability. The social model has led to a fundamental shift in the understanding of disability in the UK and well beyond, and underpins the UNCRPD. It is arguable, however, that the Framework would be strengthened by a greater critical engagement with the model to ensure that statements of commitment to it do not become a substitute for its effective implementation. Equally, if the social model is to be the underpinning principle of Action on Disability, greater care needs to be taken with the language in the document. Under the social model, disability is critically distinct from impairment. 32 This distinction is carefully explained in Action on Disability, but the document also contains statements in which these ideas are conflated. 33

Social care and independent living

For many disabled people, particularly those with the most severe impairments, adequate and appropriate social care support 34 is essential to live a full, active and equal life in the community. This group may form a minority of all disabled people, 35 but it is the group most likely to be denied independent living. While independent living is by no means solely enabled by social care, 36 for those who need such

32 Under the social model, ‘impairment’ refers to a characteristic of a person and ‘disability’ to the inequality or disadvantage experienced by the person with an impairment as a result of social barriers.
33 For example, Article 23 provides that children who have any kind of disability should have special care and support so that they can lead full and independent lives’ (page 13) and ‘Individuals who reported a long-standing illness, disability or infirmity had a significantly lower WEMWBS score (48.5) than those that did not (52.8)’ (page 23). It should be noted that both of these statements referred to external documents, the language of which was not under the control of the authors of Action on Disability. However, Article 23 of the UNCRC uses the phrase ‘disabled child’ and the statistics referred to here were reported by the Welsh Government, which adopted the social model in 2002.
34 The term ‘care’ is contentious in this context, and has been rejected by disabled activists, as it reinforces narratives of helplessness and dependency that disabled activists in the UK have rejected. It is used here to refer to support provided through local authority social services, which is still typically referred to as ‘social care’. The term used in the Social Services and Well-being Act 2014 is ‘care and support’.
35 The 2013 Framework states that ‘[o]ne in five people of working age in Wales have some form of disability or impairment’ (page 10). It also states that the number of disabled people receiving ‘social services care’ was not known, but that ‘[a]round 1.5% of the population aged 18-64 years received social service care’ (page 45). In May 2018 1,300 people were receiving direct payments from the Welsh Independent Living Grant, the successor to the Independent Living Fund. Paul Martin, ‘Welsh Government under pressure over disabled grant’ (BBC News, 9 May 2018) https://www.bbc.co.uk/news/uk-wales-politics-44055244 accessed 13 December 2013.
36 As the 2013 Framework identified, other enablers are also critical, including – but not limited to – access and barrier removal, appropriate housing, information, advocacy, peer support, and technical aids and equipment. Twelve ‘basic needs’ or ‘pillars’ of independent living have been identified, emerging and developing from an initial five that were identified in the USA in the 1970s. Jenny Morris, ‘Barriers to Independent Living: A Scoping
assistance it remains critical if they are to have active and self-determined lives and to fulfil their roles as citizens: as parents, employees, students, consumers, carers, volunteers, friends and neighbours.\textsuperscript{37} It is odd, therefore, that discussion of social care support is largely omitted from \textit{Action on Disability}. In particular, the Social Services and Well-being Act 2014 is not mentioned in the discussion of the underpinning legislation in Chapter 1. Guidance under the 2014 Act places a requirement on those acting under it to have due regard to the UNCRPD\textsuperscript{38} and also references the 2013 Framework.\textsuperscript{39} As such it is one means by which disabled people in Wales access rights under the Convention, including the right to independent living. The 2014 Act should therefore be considered a central aspect of the legal structure set out in Chapter 1 of the Framework, and the importance of social care fully acknowledged.

In the event, the connection between adequate social care support and independent living – and the need for individuals to have choice and control over assistance – is underdeveloped in the Framework, despite the reference to the right to ‘practical assistance and support’ in the definition of independent living cited above. Certain concerns about social care provision, such as lower allocations of direct payments leading to isolation – which should be a matter of grave disquiet – are raised, but are not explored or tackled.\textsuperscript{40} Similarly, there is no discussion on the closure of the Welsh Independent Living Grant (WILG) and the possible consequences of this.\textsuperscript{41} The new Framework created an opportunity for the Welsh Government to reconsider its decision not to embed either the UNCRPD or a right to independent living in domestic legislation in Wales – matters for which the disabled people’s movement in Wales has consistently lobbied.\textsuperscript{42} Despite statements of support for the incorporation


\textsuperscript{37} It should be noted that independent living was developed by activists with severe impairments who required assistance in activities of daily living and who were rebelling against their effective incarceration in residential institutions where they were subject to deeply restrictive regimes. See, for example, Jenny Morris, ‘The Meaning of Independent Living in the 3rd Millennium’ (1999, unpublished) https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/morris-The-meaning-of-independent-living-in-the-new-millenium.pdf accessed 11 December 2018.


\textsuperscript{40} For further comment on this and on other issues in \textit{Action on Disability} in relation to social care, 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.

\textsuperscript{41} Information about the impacts of the closure of the Welsh Independent Living Grant, and a campaign to save it can be found at https://nathanleedavies.wordpress.com/save-wilg-campaign/ accessed 14 December 2018.

of the UNCRPD into Welsh legislation by Assembly Members, this opportunity has not been taken and no discussion of this matter is provided in the document.

**Employment**

*Action on Disability* contains a strong focus on employment, and the responsible Minister dwelt in particular on employment in her statement on the document when it was introduced to the Assembly. There are good reasons for this. Employment is one of the 12 pillars of independent living identified by the UK disabled people’s movement, and gross inequalities in relation to employment persist for disabled people in Wales. There are grave concerns, however, about an increasing emphasis by the UK government on employment in relation to disabled people, and the focus on economic productivity as the core measure of people’s worth. The 2013 Framework took pains to make clear that all social involvement by disabled people was welcomed. It stated:

> 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.

In the light of the current concerns about the pressure on disabled people to undertake paid work, and the under-valuing of those who cannot, a similar statement would be beneficial in the revised document. Without this, the Welsh Government runs the risk of falling into narratives of self-reliance and economic productivity that are currently so damaging to many disabled people.

**The language of Action on Disability**

Despite the expanded definition provided in *Action on Disability*, there are hints in the document that the Welsh Government has not yet fully understood the concept of independent living. This is a historical problem - during the passage of the 2014 Act, the responsible Minister confused independent living with a ‘service model’. In other documents, the Welsh Government uses the phrase ‘independent living’ in relation to housing, to refer to the idea of living in one’s own home.


43 See, for example, Plenary Debate, 10 October 2018, paragraphs 255-307.

44 The Welsh Government argues that the legal and policy framework in Wales, including *Action on Disability*, already provides an adequate mechanism for the protection of the Convention rights. See the statement of Julie James in the Plenary debate cited above on 10 October 2018, paras 295-301.

45 Plenary Debate, 16 October 2018, 305-312.

46 Ibid, paragraph 309. The Minister stated: ‘Just 45 per cent of working-age disabled people in Wales are currently in employment, compared to 80 per cent of those not disabled.’ See also *Action on Disability*, page 21.

47 See, for example, Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation, 2011).


50 See pages 18, 19 and 22.
principles of independent living, but these are not the sole elements. Aids and adaptations to enable people to live in their own homes are essential, but it must not be assumed that if a person is living in their own home, they have an active, fulfilled life either within or outside it.

Conclusion

Action on Disability has been nearly two years in development. It has been taken forward by a Government that is legally required to take account of the equality of citizens and fulfil certain obligations under international human rights treaties; and which has gained substantial new legislative and fiscal powers since the publication of the 2013 Framework. It is frustrating that the document, in its current format, gives no real sense of how the Welsh Government intends to use its developing remit to tackle the structural social disadvantages still faced by disabled people in a co-ordinated, systematic way.

If disabled people in Wales are to live as full citizens, equal in self-determination, participation and worth, we need to see from the Welsh Government greater vision, greater ambition and greater willingness to place specific requirements on itself and on other state and independent agencies that lead towards progressive, targeted change. Above all, the Welsh Government needs to grasp that this document provides a powerful and exciting opportunity to create something new and radical for disabled people in Wales and to seek to exploit that opportunity to its fullest ability, with transparency about its limitations and challenges, and clarity as to how these will be overcome. There are real hints in the early part of the Framework of the transformative power of independent living and the social model of disability. The document needs to give a clearer sense of the underlying priorities and strategy that will lead towards a Wales in which disabled people are living active, fulfilled and self-determined lives, free from socially imposed barriers and on an equal basis as their non-disabled peers.