

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 92

Ymateb gan: | Response from: Dr Alison Tarrant, Lecturer in Law, Cardiff University School of Law and Politics





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Annwyl Mr George,

The Senedd Cymru Health and Social Care Committee is currently consulting on its priorities for the Sixth Senedd. My research into Welsh social care policy and law has revealed a number of issues which are likely to be of interest to the Committee. I would like to draw your attention to a short report which outlines these issues. The report is attached.

There is no doubt that various reforms are required to social care in Wales. The current arrangements are in danger of collapse, and pressures on social care provision have been exacerbated by the Covid-19 pandemic. The recent announcement by the UK government of the intention to create a health and social care levy has both indicated the direction of travel for social care policy in England and created a source of new funding that will be made available in Wales in relation to health and social care. This creates new opportunities for social care reform in the Welsh context.

All the parties now represented in the Senedd made manifesto commitments in relation to social care. These typically focused on tackling problems in the existing system. Social care is, however, not meeting the needs of those who use it. This report argues that there is now a pressing need to re-think the purpose of social care, particularly in the light of discussions within the Senedd relating to the development of domestic human rights legislation. Key points include:

- Social care is fundamental if those who need assistance in day-to-day life are to live full lives on an equal basis with others and in accordance with their human rights. If the human rights of disabled and older people are to be realised, adequate and appropriate social care is fundamental. Conversely, if social care fails or is inadequate, there is a risk that individuals' human rights will be consistently breached.
- Reform of social care should be based on the premise that it is a source of social value and a means to enable social justice. Moving away from the current policy narratives of unwelcome 'dependence' is essential.
- Direct payments are stated to be a core element of social care policy and law in Wales, and have scope to significantly improve support for those who wish to use them. However, difficulties in policy, law and implementation are ongoing in Wales. These include: low take-up and a lack of awareness of entitlement to direct payments among social care users, limited access to peer support, a lack of entitlement to direct payments where support is funded by the NHS, and policy reticence around the use of personal assistance. If direct payments are to be effectively used in Wales, these barriers must be better understood and resolved.
- The strong commitment to human rights across the political spectrum in Wales creates a unique opportunity for discussion of the purpose of social care, and a platform for overarching reform which constructs social care as a positive force for social justice. This could lead the way in the UK.

I would like to draw your attention to Article 4(3) of the Convention on the Rights of Persons with Disabilities, which requires policy makers to 'closely consult with and actively involve' disabled people and their representative organisations when developing policies and legislation which impact on disabled people. I would therefore respectfully suggest that any reform to social care must be undertaken by policy-makers working in tandem and preferably in co-production with disabled and older people and their representative organisations.

Thank you for considering this letter and the attached report. If you require any further information or would like to discuss any of the issues raised in greater detail, please do not hesitate to contact me.

Yours sincerely,

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Wales Governance
Centre

ADULT SOCIAL CARE REFORM IN WALES

DR ALISON TARRANT

SEPTEMBER 2021

PREFACE

About Us

The Wales Governance Centre is a research centre that forms part of Cardiff University's School of Law and Politics undertaking innovative research into all aspects of the law, politics, government and political economy of Wales, as well as the wider UK and European contexts of territorial governance. A key objective of the Centre is to facilitate and encourage informed public debate of key developments in Welsh governance not only through its research, but also through events and postgraduate teaching.

About the author

Dr Alison Tarrant is a Lecturer in Law at Cardiff University, specialising in disability rights, social care and social care regulation in the Welsh and the UK contexts.

Acknowledgements

The author would like to thank Professor Richard Wyn Jones, Dr Emily Kakoullis, Professor Debbie Foster, Ann James and Luke Nicholas for their help in producing this report. Thanks are also due to the Economic and Social Research Council, which funded the research upon which this report is based. The content, views and any errors are solely the responsibility of the author.

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ADULT SOCIAL CARE REFORM IN WALES

EXECUTIVE SUMMARY

Social care in Wales is in crisis. In recent years increasing numbers of people have been unable to access adequate or appropriate support, providers have relinquished unsustainable contracts with local authorities, careworker vacancies have increased, and informal carers have been pushed to their limits. These difficulties have been exacerbated by the Covid-19 pandemic, which has also revealed that the rights of older and disabled people receiving social care support are not always being upheld. It is essential that social care is stabilised in Wales as a matter of urgency.

The need for social care reform is now broadly accepted. However, discussion remains focused on financing social care, and adjustments to the existing structures and forms of support. These are not currently achieving what is needed. Reform must be about something other than perpetuating what we have. This report focuses on two aspects of social care in Wales where reform is needed: exploring and reconceptualising the purpose of social care, and policy and provision of direct payments.

Consideration of the purpose of social care is particularly necessary in the light of the potential incorporation of the UN Convention on the Rights of Persons with Disabilities (UNCPRD) into Welsh domestic law. The UNCPRD articulates the right of disabled people to live their lives on an equal basis with others, in terms of all life opportunities. Social care is fundamental to thousands of disabled and older people if they are to exercise this right, and must be understood as such.

Discussion of social care in Wales is still dominated by narratives of individual dependency and reliance. The current legislative framework constructs social care as a 'last resort'. Rather than maintaining this view of social care as an unwelcome necessity for some, reform should be centred on the principle that it is a valuable and desirable resource which liberates those using it and is fundamental to the realisation of social justice, equality and people's basic human rights.

Direct payments offer people who use social care more control over their support and their lives. They are stated to be a central element of social care provision in Wales. There remain, however, a number of ongoing problems around their use in the Welsh context. These include low take up and a lack of awareness of entitlement to direct payments among social care users, limited access to peer support, a lack of entitlement where support is funded by health, and policy reticence around the use of personal assistance. If direct payments are to be effectively used in Wales, these barriers must be better understood so that they can be removed. The ways to remove them need to be developed by policy-makers working together with disabled and older people and their representative organisations.

1. INTRODUCTION

As in other parts of the UK, social care in Wales has been in 'crisis' for some time. This has been exacerbated by the Covid-19 pandemic, and the Senedd Research service recently suggested that social care in Wales may be at 'breaking point'.¹ This is no longer a matter of debate. Even before the pandemic, social care providers in Wales were terminating contracts with local authorities as they were unable to provide an adequate level of support for the purchase price.² Difficulties emanating from the fragmentation of the social care system, the lack of resources, and inadequate terms and conditions of employment for careworkers are documented in Wales as in other parts of the UK.³ Covid-19 deepened these pre-existing problems. During the pandemic, social care packages were 'pared back' with increased expectations placed on informal carers,⁴ and evidence suggested that equality and human rights standards in social care were not always upheld.⁵

In recent weeks the crisis has intensified. A number of local authorities in Wales have stated a need to reduce care packages as a result of staff shortages,⁶ requesting informal carers – who are already under immense strain – to take on yet more responsibilities.⁷ In some cases, these include nursing duties for which training is required.⁸ Even if this is a temporary measure, these actions are indicative of a system that is no longer functional and fit for purpose. The core priority for social care in Wales is stabilisation of a system that is now clearly at risk of collapse.

This report focuses on aspects of social care that require examination and consideration once this immediate crisis is resolved. It is based on research carried out by the author into the content of social care policy and law in Wales. Its core focus is whether the current understanding of adult

¹ Amy Clifton, 'Social care: A system at breaking point?' (*Senedd Research*, 17 May 2021)

<<https://research.senedd.wales/research-articles/social-care-a-system-at-breaking-point/>> accessed 7 June 2021.

² BBC News, 'Home care firms in Wales facing "desperate" pressures' (BBC News, 20 March 2017)

<https://www.bbc.co.uk/news/uk-wales-39321818> accessed 2 September 2021.

³ Cian Siôn and Michael Trickey, 'The future of care in Wales: Resourcing social care for older adults' (Wales Governance Centre, Cardiff University 2020).

⁴ Senedd Cymru Health, Social Care and Sport Committee, 'Inquiry into the impact of the COVID-19 outbreak, and its management, on health and social care in Wales: Report 3 – Impact on the social care sector and unpaid carers' (Senedd Cymru, March 2021) para 106.

⁵ Equality and Human Rights Commission, 'Equality and human rights in residential care in Wales during coronavirus' (October 2020); Debbie Foster and others, 'Locked out: Liberating disabled people's lives and rights in Wales beyond COVID-19' (Welsh Government, 2021) <https://gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19> accessed 14 September 2021.

⁶ Becky Hotchin, 'Pembrokeshire County Council contingencies for Brexit and Covid carer shortage' (The Western Telegraph, 30 July 2021) <https://www.westerntelegraph.co.uk/news/19477867.pembrokeshire-county-council-contingencies-brexit-covid-carer-shortage/> accessed 31 August 2021.

⁷ Carers Wales, 'Unpaid carers in Gwent, and across Wales, urgently need clarity about extra demands being placed on them in light of social care reductions' (Carers Wales, 19 August 2021) <https://www.carersuk.wales/news-campaigns/news/unpaid-carers-in-gwent-and-across-wales-urgently-need-clarity-about-extra-demands-being-placed-on-them-in-light-of-social-care-reductions> accessed 1 Sept 2021.

⁸ BBC News, "'Alarming" Swansea carer shortage prompts family SOS call' (BBC News, 30 July 2021) <https://www.bbc.co.uk/news/uk-wales-58025444> accessed 1 September 2021.

social care in Wales is appropriate to meet the needs of the people who use it. *The report argues that there is a need to reconceptualise the purpose of social care in Wales and that reforms must be guided by this reconceptualisation.* It relates in particular to working-age people who need assistance in daily life, their entitlements under the UN Convention on the Rights of Persons with Disabilities (UNCRPD),⁹ and their right to independent living under this Convention. However, the content of both the UNCRPD and this report is also relevant to other demographic groups who use social care, including older people.

The current Welsh Government has stated its intention to incorporate the UNCRPD into Welsh domestic law,¹⁰ and support for its incorporation is broad in the Senedd. The Welsh Liberal Democrat manifesto 2021 endorsed incorporation,¹¹ and in hustings prior to the 2021 election representatives of all the parties now represented in the Senedd made similar commitments. The report commissioned by the last Welsh Government on strengthening and advancing equality and human rights in Wales has recently been published and recommends incorporation.¹² This is an important discussion for Wales, potentially leading to progressive constitutional developments. It does, however, mean that alongside the need to solve the immediate crisis in social care, it is necessary to consider whether the scope and format of social care are adequate to uphold the rights enshrined in the UNCRPD. The Welsh Government has recently acknowledged that there is a need to 'develop different and improved approaches to social care',¹³ and there is underlying acknowledgment that social care is not achieving all it could. The development of a national social care framework is anticipated.¹⁴ However, discussion remains focused on the adjustment of what currently exists rather than consideration and exploration of what social care could, and should, achieve.

This report sets out the importance of adult social care to the realisation of UNCRPD rights and indicates why we need to undertake a 're-think' of social care. It focuses on two core areas: a) the overall purpose of social care; and b) direct payments. Recent research, including the evaluations of the Social Services and Well-being (Wales) Act 2014 indicate that there are other key areas where more knowledge and further action are required, which fall outside the scope

⁹ In Wales, the UNCRPD is also referred to as the 'UN Convention on the Rights of Disabled People' or 'UNCRDP' as this language reflects the social model of disability.

¹⁰ Minister for Social Justice, 'Written statement: Welsh Government response to the Locked out: Liberating disabled people's lives and rights in Wales beyond Covid-19 report' (2 July 2021) <https://gov.wales/written-statement-welsh-government-response-locked-out-liberating-disabled-peoples-lives-and-rights> accessed 2 September 2021.

¹¹ Welsh Liberal Democrats, 'Put recovery first' (2021) <https://www.welshlibdems.wales/manifesto> accessed 10 September 2021.

¹² Welsh Government, 'Strengthening and advancing equality and human rights in Wales' (26 August 2021) <https://gov.wales/strengthening-and-advancing-equality-and-human-rights-wales> accessed 2 September 2021.

The Welsh Government funded enquiry into the impact of Covid-19 on disabled people in Wales also recommended incorporation of the UNCRPD. See, Debbie Foster and others, 'Locked out: Liberating disabled people's lives and rights in Wales beyond COVID-19' (Welsh Government, 2021) <https://gov.wales/locked-out-liberating-disabled-peoples-lives-and-rights-wales-beyond-covid-19> accessed 14 September 2021.

¹³ Welsh Government, 'Improving health and social care (Covid 19 looking forward): Social care recovery framework (2021) <https://gov.wales/social-care-recovery-framework-covid-19> accessed 14 September 2021.

¹⁴ Welsh Government, 'Programme for Government' (2021) <https://gov.wales/programme-for-government-2021-to-2026> accessed 14 September 2021.

of this report. In particular, these include advocacy, co-production, and the urgent need to ensure that informal carers are both adequately supported and not expected to undertake tasks that have an undue impact on their own lives, are beyond their ability or personal limits, or which are better carried out by others. It is also vital that attention is paid to the terms and conditions of employment for care workers, to ensure that they are properly rewarded and respected for the challenging and skilled work that they undertake, and that they receive proper training to carry out their role. Action is needed in all of these areas as a priority.

Under Article 4(3) of the UNCRPD, policy makers are required to 'closely consult with and actively involve' disabled people and their representative organisations when developing policies and legislation which impact on disabled people. Any policies relating to independent living, social care and direct payments should therefore be developed in close consultation with disabled people's organisations and with people who use social care.

2. INDEPENDENT LIVING

If the UNCRPD is to be incorporated into Welsh law, the concept of 'independent living' must be fully understood by policy makers at national and local level, and by all those working in social care. Independent living was created by disabled activists between the 1970s and 1980s. It is essential to understand that in the context of disability independent living does **not** mean living alone or doing things for oneself – although it is commonly misunderstood and applied in this way. Confusion arises for two reasons. Firstly 'independence' has many meanings, including self-reliance, which creates possibilities for misinterpretation. Secondly, in certain policy contexts (particularly around looked-after children and older people) the term 'independent living' frequently refers to ideas such as 'doing for oneself'. Within the disabled people's movement however, 'independent living' refers to the ability and the right of disabled people to live their lives on an equal basis with others. John Evans, one of the pioneers of independent living in the UK described it 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".¹⁵

Independent living is now enshrined as a right under the UNCRPD. Article 19 – 'living independently and being included in the community' – is one of the Convention's pivotal provisions. It states that all States Parties shall:

¹⁵ 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.

“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”.

To this end, States Parties must ensure that (in summary):

- a) Disabled people have opportunities equal to others to choose their living arrangements including where and with whom they live;
- b) Disabled people have access to domiciliary, residential and community support services which supports them to live in and be included in the community, and to prevent isolation and segregation, including access to personal assistance.
- c) General community services and facilities are available to disabled people on an equal basis with others and are responsive to their needs.

Article 19 concerns equal life expectations, responsibilities and fulfilment,¹⁶ and is fundamental to the realisation of other rights in the UNCRPD. Without a home of one’s own in the community, other rights such as the ability to work, receive a full education, or raise a family are compromised.¹⁷ Other provisions of the Convention also relate to independent living, in that they articulate rights to specific economic, social, and cultural activities that are necessary if disabled people are to live their lives on an equal basis with others.

Independent living is closely connected to the social model of disability. This states that disability does not arise from impairments – which form a natural part of the human condition – but from social failings to accommodate impairment. The Welsh Government has recently restated its commitment to the social model of disability, which it adopted in 2002;¹⁸ and has to date developed its disability policy around the principle of independent living.¹⁹ Despite this, independent living has historically been imperfectly understood within the Welsh context, including at governmental and Senedd level.²⁰ It is vital that this is now rectified.

3. THE IMPORTANCE OF SOCIAL CARE TO INDEPENDENT LIVING AND UNCRPD RIGHTS

¹⁶ See further, the general comment on article 19: Committee on the Rights of Persons with Disabilities, ‘General comment No 5: Article 19: The right to independent living’ (adopted 31 August 2017, available at: <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx> accessed 2 September 2021).

¹⁷ Arlene Kanter, *The Development of Disability Rights under International Law* (Routledge 2015) 12.

¹⁸ Deputy Minister and Chief Whip, ‘Written statement: The rights of disabled people in Wales’ (24 March 2021) <https://gov.wales/written-statement-rights-disabled-people-wales> accessed 2 September 2021.

¹⁹ The first pan-disability strategy in Wales was ‘The framework for action on independent living’ (Welsh Government, 2013). This was replaced in 2019 with ‘Action on disability: The right to independent living’ (Welsh Government 2019).

²⁰ For example, during the passage of the 2014 Act, both the relevant Deputy Minister and the then Health and Social Care Committee understood independent living to be a ‘service model’ of social care provision and/or relating to ‘suitable housing’. See National Assembly for Wales Health and Social Care Committee, ‘Social Services and Well-being (Wales) Bill: Stage 1 Committee Report’ (July 2013) paragraphs 69 to 70.

The essential element of Article 19 of the UNCRPD is its express statement that disabled people are entitled to a life in the community and equal life choices as other people. Article 19 and the UNCRPD more broadly require such equality *in all respects*. States Parties must ensure that disabled people have opportunities to work on an equal basis with others, and are able to access community facilities such as shops, banks and cinemas. The UNCRPD enshrines the rights of disabled people to take on family responsibilities such as parenting, looking after grandchildren, or supporting parents as they age; to meet and socialise with friends at any time of the day or night, to take up and pursue hobbies and leisure activities, to vote or run for public office, or to eat a meal of their choice at the time of their choice. Thousands of disabled and older people in Wales need social care support if they are to undertake one, or some, or all of these activities. If rights under the UNCRPD are to be realised, it follows that we must ensure that social care support in Wales is formed around the provisions and principles of the Convention, particularly Article 19.

The Welsh Government strategy on disability – Action on Disability: The Right to Independent Living – is (as its name indicates) stated to be centred around the concept of independent living.²¹ There are, however, various difficulties with this document. It includes an explanation of Article 19 which does not fully reflect the content of the provision,²² and there is a lack of exploration of the vital role of social care in enabling independent living. There is, perhaps, a sense that the Social Services and Well-being (Wales) Act 2014 has achieved the necessary reforms. This Act and accompanying legislation and guidance has certainly placed a focus on putting personal outcomes at the heart of social care. It also requires local authorities to ‘promote the involvement of persons for whom care and support or preventative services are to be provided in the design and operation of that provision’,²³ and the guidance contains multiple references to co-production. However, the recent evaluation of the impact of the 2014 Act, ‘Measuring the Mountain’ (2020),²⁴ demonstrated that in practice, social care is not yet enabling people to live the lives of their choice and is sometimes very far from doing so. For example:

“When the local authority assessed my hours I had to write a day plan of what each hour would be for and to justify and explain every hour. I’ve been assessed as needing 53.75 hours week - getting up takes an hour and bowel care takes 1.5 hours every day - that’s a third of those hours gone. Socialisation ... isn’t seen as important, it’s not valued... If I want to do anything extra - go out for my birthday, for example, I’ve got to work all the hours out to make sure I’ve got enough.”²⁵

²¹ Welsh Government, ‘Action on disability: The right to independent living’ (2019) <https://gov.wales/action-disability-right-independent-living-framework-and-action-plan> accessed 7 September 2021.

²² Alison Tarrant, ‘Analysis of *Action on disability: The right to independent living*’ <http://www.lukeclements.co.uk/wp-content/uploads/2018/12/2018-08-Action-on-Disability-Final.pdf> accessed 2 September 2021.

²³ Section 16(1)(c).

²⁴ Rachel Iredale and Katie Cooke, ‘Measuring the mountain: Understanding what matters in social care: Experiences of care and support services and being an unpaid carer in Wales’ (University of South Wales, 2020) <http://mtm.wales/ckfinder/userfiles/files/Measuring%20the%20Mountain%20Story%20Gathering%20FINAL%20REPORT%202020.pdf> accessed 2 September 2021.

²⁵ *Ibid*, 51.

"There should be more support to go out in the evening. I only go out in the evening every two weeks unless there is a party. ... I would like to do more in the evening so I don't feel so lonely sitting in my annex by myself."²⁶

"I am a lady in my mid-thirties. I suffer from Down syndrome and am registered blind and deaf. I am non-verbal and use a wheelchair. I also have learning difficulties. People often talk about me rather than to me and presume that because I am non-verbal I do not / cannot be included in a conversation even when it relates to me. I have an AAC app on my iPad for communication but require support to learn and maintain my use. Some of my support staff will use it, but many others won't, so I often do not get the chance to make my own decisions and speak up. Because my behaviours are sometimes challenging, my iPad is used as a punishment and not given to me. Staff also place me in a low stimulation environment, which further restricts my ability to interact with others. As a result I get extremely frustrated which is often misinterpreted as challenging behaviour. Someone please take notice of me."²⁷

4. THE PURPOSE OF SOCIAL CARE

Social care policy in Wales is currently dominated by a narrative of individual dependency and reliance, rather than discussed in terms of its social value and its connection to human rights, dignity and respect. The need to use social care support is typically framed as a problem, or as something to be overcome. This both reflects and leads to policy that is specifically focused on *reducing* social care use. Despite the wellbeing duty introduced by the Social Services and Well-being (Wales) Act 2014, this 'dependency and reliance' narrative persists in Wales, including in documents related to the Act including guidance and explanatory memoranda. For example:

"The [Information Advice and Assistance service] approach **must** be proactive – empowering staff to encourage people to seek help earlier and supporting them to **help themselves to retain their independence** in a proportionate way."²⁸ (Second emphasis added.)

The same narrative is seen elsewhere. For example, the Measuring the Mountain report states:

"Some stories contained examples of people who wanted to live fulfilled, busy lives **but** who were **reliant** on care and support services to enable this."²⁹ (Emphases added).

²⁶ Ibid, 54.

²⁷ Ibid, 52.

²⁸ Welsh Government, 'Social Services and Well-being (Wales) Act 2014: Part 2 Code of Practice (General Functions)' (Welsh Government 2015) para 309.

²⁹ Rachel Iredale and Katie Cooke, 'Measuring the mountain: Understanding what matters in social care: Experiences of care and support services and being an unpaid carer in Wales' (University of South Wales, 2020) para 6.24

<http://mtm.wales/ckfinder/userfiles/files/Measuring%20the%20Mountain%20Story%20Gathering%20FINAL%20REPORT%202020.pdf> accessed 2 September 2021.

During the passage of the 2014 Act, independence was cited as one of its core principles.³⁰ The statute itself contains two provisions relating specifically to individual independence. Section 6(3)(b) places those acting under the Act under an overarching duty to have regard to of 'the importance of promoting the adult's independence where possible'. Section 15(2) requires local authorities to provide or commission preventative services which contribute 'towards preventing or delaying the development of people's needs for care and support', or which reduce people's need for care and support; or which enable 'people to live their lives as independently as possible'. The guidance links the section 6 duty to independent living,³¹ and discussion of independence in documents relating to the 2014 Act is frequently connected to the language of autonomy. However, in these documents, independence is more typically framed as self-reliance and connected to a *reduction* in social care use. For example, the explanatory memorandum to the Care and Support (Eligibility) (Wales) Regulations 2015 states that the core objective of the Regulations is 'to promote an individuals' (sic) independence'.³² Specifically the intention of the eligibility approach 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".³³

Prior to the introduction of the 2014 Act and during the consultation on the guidance and the regulations, the purpose of social care was stated to be to do what was once described as 'the minimum necessary'.³⁴ The policy aim was apparently to develop greater non-statutory community capacity.³⁵ This is reflected in the eligibility criteria, which establish that a person is only eligible for social care if (among other things) they cannot meet their personal needs alone, with the support of others, or through existing community services. In other words, in Wales social care is legally expressed as a 'last resort', to be used only where other options are not available.

It is of course the case that people typically wish to do what they can for themselves. Similarly, reablement is an important role of *some* social care provision. It is also necessary to ensure that social care resources are used effectively, particularly in times of exceptional fiscal constraints. However, we must also understand that a focus on self-reliance for its own sake is not necessarily

³⁰ 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.

³¹ The final version of the guidance to Part 2 of the 2014 Act stated in discussion of the 6(3)(b) duty that: 'Well-being is defined in relation to all aspects of a person's life. 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". Welsh Government, 'Social Services and Well-being (Wales) Act 2014: Part 2 Code of Practice (General Functions)' (2015) para 56.

³² Welsh Government, 'Explanatory memorandum to the Care and Support (Eligibility) (Wales) Regulations 2015' (2015), 6.

³³ *Ibid* 6-7.

³⁴ 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 3 September 2021.

³⁵ See, Welsh Assembly Government, 'Sustainable social services for Wales: A framework for action' (2011).

a form of social value. As an example, if a disabled person *can* complete the tasks of a morning routine without support but is left with so little time and is so fatigued that their ability to carry out further activities is curtailed, independent living and social contribution are denied. In contrast, if they have access to social care support to assist them in their morning routine, their time and capacity is freed up for activities that extend beyond mere survival. It is also important to acknowledge that informal support and generic services do *not* necessarily support, and may actually negate, independent living. Indeed, the concept of independent living emerged among disabled people precisely as a response to the limitations of family support and the failings of generic services.³⁶ We must recognise that ***social care is a positive and welcome force for good, which enables people to live the life of one's choice and contribute to their communities and to society.***

Necessary actions

If rights are to be a priority in Wales, two things are essential in the context of social care. Firstly, the concept of independent living must be better and more widely understood and the content of Article 19 and other provisions within the UNCRPD must underpin policy development. Secondly, we must reject the current dominant narrative that the use of social care is unwelcome or a 'problem' for the user, or something that should be relinquished as soon as possible. We must, as a matter of priority, start to view and treat social care as a valuable and desirable resource which liberates those using it and is fundamental to the realisation of social justice, equality and people's basic human rights.

5. DIRECT PAYMENTS

Direct payments – or the provision of cash in lieu of services – have historically been fundamental to social care provision which enables independent living in the UK. In particular, disabled people have used direct payments to purchase personal assistance, usually through becoming direct employers of personal assistants (PAs).³⁷ Employing one's own PA/s enables the highest level of control over one's support, but is not a model that suits all social care users. Similarly, not all social care users wish to receive direct payments. Personal assistance, however obtained, is explicitly referenced as a form of support in Article 19 of the UNCRPD.

Direct payments have been stated by successive Welsh Governments to be a key aspect of social care provision in Wales and were extended under the Social Services and Well-being (Wales) Act 2014. There are, however, a number of ongoing difficulties in the Welsh context which require attention. These are:

³⁶ See, for example, Hampshire Centre for Independent Living, 'Project 81: One Step On' (unpublished and undated) <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/HCIL-facing-our-future.pdf> accessed 3 September 2021.

³⁷ For example, Colin Barnes (ed), 'Making our own choices: Independent living, personal assistance and disabled people' (British Council of Organisations of Disabled People 1992) <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-making-our-own-choices.pdf> accessed 2 September 2021.

5.1 Lack of knowledge / promotion of direct payments

Direct payment take up is low in Wales, and has always been so.³⁸ The Measuring the Mountain report (2020) indicated that – some four years after the implementation of the 2014 Act – social care users are not routinely being made aware of direct payments or their entitlement to them, and that confusion around direct payments is common.³⁹ If the Welsh Government wishes direct payments to be a meaningful element of social care policy and provision, it is essential that there is greater understanding of them and that the reasons for low uptake are properly understood.

5.2 Lack of access to peer support

Access to peer support has always been a key element of the implementation of independent living.⁴⁰ It is particularly necessary where individuals wish to use direct payments and personal assistance, particularly if they wish to become PA employers. Organisations run and staffed by disabled people, including centres for independent living (CILs) and disabled people's organisations (DPOs), are a core form of peer support. There are few CILs/DPOs in Wales, and while an increase in the number of disabled people with access to a CIL was a core target of the Welsh Government's first pan-disability strategy in 2013,⁴¹ there is little evidence that this has been effectively achieved.

5.3 The interface between direct payments and NHS-funded support

Welsh legislation prohibits the use of direct payments where people's care packages are funded by the NHS. This affects those with the most severe impairments. It creates particular difficulties for people who are 'moved' from local authority funding to NHS continuing health care (CHC) funding as a result of policy developments, such as closure of the Welsh Independent Living Grant, or where their condition changes. Some individuals transitioning between local authority social care and CHC-funded support have been placed at risk of losing their existing support team, causing immense distress. In certain cases, individuals have been required to choose between community-based support which does not enable them to maintain their existing level of autonomy and activity, institutionalisation, or being left without care.⁴² In its 2021 Programme for Government, the Welsh Government has committed to 'improv[ing] the interface between continuing healthcare and Direct Payments',⁴³ but the matter is incompletely

³⁸ G Atkins, G Dalton and others, 'Devolved public services: The NHS, schools and social care in the four nations' (Institute for Government, 2021); Mark Priestley and others, 'Direct payments and disabled people in the UK: Supply, demand and devolution' (2007) 37 *British Journal of Social Work* 1189-1204.

³⁹ Rachel Iredale and Katie Cooke, 'Measuring the mountain: Understanding what matters in social care: Experiences of care and support services and being an unpaid carer in Wales' (University of South Wales, 2020) <http://mtm.wales/ckfinder/userfiles/files/Measuring%20the%20Mountain%20Story%20Gathering%20FINAL%20REPORT%202020.pdf> accessed 2 September 2021.

⁴⁰ John Evans, 'The role of centres of independent/integrated living' in Barnes (ed) 'Making our own choices: Independent living, personal assistance and disabled people' (British Council of Organisations of Disabled People 1992) <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-making-our-own-choices.pdf> accessed 2 September 2021.

⁴¹ Welsh Government, 'Framework for action on independent living' (2013).

⁴² Anecdotal evidence provided in confidence to the author by e-mail.

⁴³ Welsh Government, 'Programme for Government' (2021) page 10.

addressed in the recently revised National Framework for NHS Continuing Healthcare.⁴⁴ Robust action to rectify this is now required.

5.4 Inadequate local authority social care resourcing

As with other forms of social care provision, the amount of support that people are receiving through direct payments is not always adequate to enable them to live full, let alone equal, lives. The Welsh Government disability strategy, 'Action on Disability: The Right to Independent Living' (2019) itself states that reductions in allocations have led to 'disabled adults and young people ... becoming increasingly isolated and ... their well-being compromised'.⁴⁵

5.5 Inconsistent policy approaches to direct payments and reticence about personal assistance

The guidance on direct payments under the Social Services and Well-being (Wales) Act 2014 is significantly less detailed than the guidance under the previous legislative framework. In addition, the specific case examples of meeting social care needs contained in the guidance under the 2014 Act make no reference to direct payment use, but refer to reablement, more 'traditional' services and informal support.⁴⁶ This contradicts the message found elsewhere in the statutory regime, including the same guidance, that direct payments are a fundamental element of the Welsh social care system which should be promoted and used as flexibly as possible. In addition, discussion of personal assistance is almost absent from policy and legislative documents in the Welsh context.⁴⁷

If direct payments are to be a fundamental aspect of social care provision in Wales, a more consistent policy approach is needed. It is vital that people in receipt of direct payments – and other forms of support provision – have genuine choice and control over how they purchase and use support, and that flexibility in the use of direct payments is embraced and promoted. It is also important that the value of personal assistance is fully understood at all stages of social care policymaking and provision. Personal assistance should be a realistic option for any individual using social care support in Wales, whether it is obtained via the use of direct payments or not. This is particularly the case in the light of Article 19 of the UNCRPD, which requires 'access to ... community support services, including personal assistance necessary to support living and inclusion in the community'.

5.6 Necessary actions

Given the above difficulties, various actions are needed if direct payments are to be effectively used in Wales. These include:

⁴⁴ Welsh Government, 'National framework for NHS continuing healthcare' (revised July 2021) <https://gov.wales/national-framework-nhs-continuing-healthcare> accessed 3 September 2021.

⁴⁵ Welsh Government, 'Action on disability: The right to independent living (2019).

⁴⁶ Welsh Government, 'Social Services and Well-being (Wales) Act 2014: Part 4 Code of Practice (Meeting Needs)' (Welsh Government 2015).

⁴⁷ See, for example, Welsh Assembly Government, 'Direct payments guidance: Community care, services for carers and children's services (direct payments) guidance Wales 2004' (2004). This document reproduced the text of the equivalent guidance drafted in Westminster for use in England, with the notable core distinction that the case studies of direct payment use – including nearly every reference to the employment of PAs – were removed.

- Independent research on the reasons for the low take-up of direct payments in Wales, how take up can be improved, how individuals wish to use direct payments and what forms of social care support people want to use where they do not wish to use direct payments.
- Research into the levels of personal assistance use in Wales, whether people are aware of and wish to use personal assistance, whether people wish to directly employ personal assistants or to obtain PA support in other ways (and, if so, what these other ways may be), and whether there are barriers to personal assistance use and how these may be overcome.
- Improving access for disabled and older people to independent and accessible peer support and advocacy in relation to social care use, direct payments and personal assistance.
- Local authorities and others acting under the 2014 Act must advise people of their entitlement to direct payments, and be able to direct individuals to accessible sources of independent information and support in using direct payments. Local authorities should also explain the concept of personal assistance and direct people to independent sources of information and support around personal assistance.

The difficulties which arise from the interface between local authority and NHS CHC funding need to be fully explored and consideration given to how these may be overcome. This work must be undertaken with disabled people who use direct payments and those whose support is funded through CHC.

6. CONCLUSION

The 2021 manifestos of every party now represented in the Senedd refer to social care. While there is some overlap in views, the discussion remains focused entirely on perpetuating and 'fixing' the system that we already have, and how this can be sustained and funded. However, social care in its current format is not meeting the needs of those who use it. We need to re-think what social care needs to achieve in Wales, and how it can support those who use it to lead full lives. This work should be led by people who use social care.

Social care cannot be separated from the human rights of those who require support in their day-to-day lives. If these rights are to be realised and disabled people are to be able to lead full and active lives on an equal basis with their non-disabled peers, adequate and appropriate social care is fundamental. Conversely, if social care fails or is inadequate, there is a risk that individuals' human rights will be consistently breached, including on a daily basis. The strong commitment to human rights across the political spectrum in Wales creates a unique opportunity in the UK for a discussion on the purpose of social care. It provides a platform for overarching reform which constructs social care as a positive force for social justice rather than a drain on resources. Such reform has the potential to lead the way in social care policy.

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