

Civil Society Shadow Report on the Implementation of the United Nations Convention on the Rights of Disabled People (UNCRDP) in Wales



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Introduction

This is a Wales-specific shadow report which follows from the 2017 report Implementation of the United Nations Convention on the Rights of Persons with Disabilities in England and Wales Shadow report conducted by Disability Rights UK and Disability Wales.

We welcome some improvements in Wales since the 2017 report, such as specific commitments to the UNCRDP¹ and the publication of an action plan on disability rights², however, attention needs to be drawn to the significant amount of progress that still needs to be made, especially as a consequence of challenges brought by the coronavirus pandemic. Last July it was reported that 68% of coronavirus-related deaths in Wales have been disabled people.³ Due to the context of devolution in the UK and the differing approach taken by the Welsh Government (WG) particularly during and post-pandemic it is important that the Committee notes the differences between Wales and the UK as a whole.

This report draws on the voices and experiences of disabled people across Wales and has been co-produced with them. In addition, a steering group was established consisting of 9 members from across academia, representing various disabled people's organisations and the equalities sector. The steering group has been involved in providing feedback and shaping the direction of the report. Some members have also been directly involved in co-designing evidence gathering events.

A call for evidence and involvement in the reporting process was promoted, through Disability Wales' own membership (485 members, inc. 29 full member Disabled People's Organisations) and through its social media platforms twitter (14.5k followers) and Facebook (4986 followers).

The call for evidence and involvement provided detail on the UN Convention on the Rights of Disabled People (UNCRDP), the 5 yearly review by the UN Disability Committee and of the fact that Disability Wales is producing a shadow report.

¹ Welsh Government, (2019), Action on Disability: The Right to Independent Living, Policy Framework - Page 6

² Welsh Government, (2019), Action on Disability: The Right to Independent Living , Policy Framework

³ Welsh Government, (July 2021), Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19 report - Page 7

This report is informed by a survey answered by 52 individuals and organisations, written evidence submissions from 5 individuals and organisations and 6 capacity building events attended by 126 people. In order to capture information from groups under-represented in research into disability rights in Wales, of the events 5 were focused on specific groups. These groups were: disabled women, disabled lesbian, gay, bisexual, transgender, queer or questioning (LGBTQ+) people, disabled people from Black, Asian and Minority Ethnic (BAME) communities, disabled people with a learning impairment or disability, and disabled people in North Wales, a largely rural part of Wales where Welsh rather than English is the first language in many of its communities.

The Welsh Context

A Note on Devolution

Since 1997 a devolved administration has been in place in Wales. The Parliament is called the Senedd, which operates a reserved powers model meaning that, with the exception of listed powers that are reserved to the Westminster Government (WeG), all other areas, subject to legal tests and certain restrictions, are assumed to be within the competency of the Welsh Government (WG)⁴⁵⁶.

This report will focus on policy areas devolved to Wales. Some reserved policy areas will be mentioned and commented on, where strictly relevant, but to do these topics the justice, they will be properly expanded on in a document containing the full UK-wide context.

It is important to emphasise that the approach to human rights, including disability rights, taken by the WG is markedly different from that of the WeG. The WG explicitly follows a rights-based approach to policymaking and has made specific commitments to following the Social Model of Disability and the UNCRDP in Wales-specific equality legislation, such as Action on Disability: The Right to Independent Living.⁷ During the pandemic WG also set up an inquiry into the impact of Covid-19 on disabled people in Wales co-produced with and by disabled people and their representatives⁸ it is the only report of its kind in the UK and has led to the establishment of a Disability Rights Taskforce by the First Minister of Wales, co-chaired by the Social Justice Minister Jane Hutt and a nominee from the WG Disability Equality Forum.⁹ One of the objectives of the Taskforce will be to revise policy to take account of disabled people's experiences during the pandemic. The governing Welsh Labour administration is also committed to enshrining the UNCRPD into Welsh law.¹⁰

⁴ Senedd Cymru, Welsh Parliament, How we work, History of Devolution 2021

⁵ Welsh Parliament, (September 2020), "Powers"

⁶ House of Commons, (February 2016), "2 Moving to a Reserved Powers Model"

⁷ Welsh Government, (2019), Action on Disability: The Right to Independent Living, Policy Framework

⁸ Welsh Government, July 2021 Locked out: liberating disabled people's lives and rights in Wales beyond COVID-19 report

⁹ Welsh Government, Written Statement: Response to the Locked Out: Liberating disabled people's lives and rights in Wales beyond Covid-19 report. Jane Hutt, Minister for Social Justice July 2021

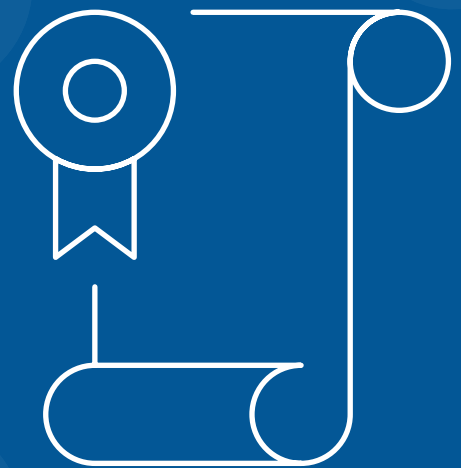
¹⁰ Welsh Government, (2022), Programme for Government – Update, p14

A Note on Terminology

Disability Wales uses UK social model language. This distinguishes between impairment and disability: the latter seen as located in society rather than the person. Language used in this report reflects the preferred terminology of disabled people's organisations in Wales. As a result, this report shall use "UNCRDP" rather than "UNCRPD."

Section One

Principles



Section One

Principles

Chapter One of Action on Disability: A Framework for Independent Living sets out the principles that the WG pledged to abide by.¹¹ In her statement on the International Day of Disabled People, Minister for Social Justice Jane Hutt MS restated these principles but also acknowledged that there is significant work still to do, particularly in the context of pre-existing inequalities exposed by the coronavirus pandemic.¹²

In the focus groups held and within comments given to questions across the survey, notably primarily when asked about articles 3 and 4, several disabled people expressed greater trust in WG intentions in developing policy than the WeG, whereas no respondents or focus group participants expressed more trust in the WeGs intentions in policy development than the WG's.¹³

¹¹ Welsh Government, 2019 Action on Disability: The Right to Independent Living , Policy Framework

¹² “It is also a terrible fact that, across the UK, six in every 10 of COVID-related deaths were of disabled people. Many of these deaths were not the simple inevitable consequence of impairment, with many deaths being clearly rooted in socioeconomic factors. Today, I’m not only reiterating that this Government recognizes these inequalities, but that we are resolute in our determination to address them and have taken significant action to do so.”, Excerpt from Plenary, Jane Hutt MS, 30/11/2021

¹³ Wales is pretty good because the [Social Services and Wellbeing Act 2014] places us and what we aspire to at the centre of policy.” One focus group participant, edited for clarity

This does not necessarily translate to high levels of trust towards the Welsh Government, in 2020 Disability Wales found that 76% of disabled people responding to a survey did not believe that their rights in Wales would improve over the next five years.¹⁴ Unfortunately, there is a lack of specific data comparing disabled people's levels of trust in WG and WeG. In terms of outcomes an implementation gap has been repeatedly identified by both survey respondents and was brought up by focus group attendees.¹⁵ One survey respondent gave the example of racism in Welsh institutions,^{16 17} this was also repeated by focus group attendees. Another survey respondent gave the example of the continued existence of ABA creches, a form of therapy considered abusive by many autistic people.^{18 19 20 21}

Recommendations for the Committee:

We recommend that the committee ask:

1. How the UK and WGs intend to successfully implement articles 2 and 3.
2. How are the Governments seeking to re-establish and fully implement the social model of disability into their policy programmes? What lessons have they been learned from the coronavirus pandemic in relation to disabled people and what policies and or approaches are they changing in consequence?

¹⁴ Megan Thomas, Disability Wales, Bring Us Our Rights Disabled People's Manifesto, (December 2020, p14)

¹⁵ While it seems as if Wales is upholding the principles there are many times when it seems as it is only paying lip service to them" Survey Respondent.

¹⁶ "I have found some institutions are institutionally racist against disabled people." One survey respondent

¹⁷ Race Equality First, "Joint NGO Shadow Report on Racial Inequality in Wales", July 2021

¹⁸ So long as LEAs (local education authorities) are paying for ABA (Applied Behavioural Analysis) to be performed on autistic children the government will fail in its duty" Disability Wales survey respondent

¹⁹ "So long as LEAs (local education authorities) are paying for ABA (Applied Behavioural Analysis) to be performed on autistic children the government will fail in its duty" Survey respondent

²⁰ Kat Williams, Republished with Autistic UK (2021), "Autistics Against ABA"

²¹ Shona Davidson, Autistic UK (2018), "Does ABA Harm Autistic People?"

Section Two

Equality and Justice



Section Two

Equality and Justice

WG has repeatedly reaffirmed a commitment to equality and non-discrimination, including making “A More Equal Wales”²² one of seven wellbeing goals in the Wellbeing of Future Generations Act (2015) and publishing a strategic equality plan and multiple specific action plans on marginalised communities.²³

The implementation gap in Welsh policy has been previously documented²⁴ its impact was clearly demonstrated in the survey responses and from the unchallenged views of disabled people who attended our focus groups. There was a clear sense of frustration at the perceived stagnation of WG policy, disabled people who responded to our survey and who attended the focus groups have told us that they feel isolated from the Government and Welsh policy making and that many of these policies haven’t resulted in a demonstrated improvement in their material circumstances.^{25 26} The WG should shift to focus on more tangible outcomes.

This issue continues into the experiences of specific groups of disabled people. We have received reports of increased harassment and difficulty accessing domestic abuse services, especially during the coronavirus pandemic.^{27 28 29} This is especially concerning as disabled women are more likely to experience domestic abuse and are more likely to be harassed and assaulted.³⁰ There are additional barriers to accessing domestic abuse shelters for disabled women as they must ensure that these services are accessible to them, they may require extra support and in some cases their abuser is also their Carer.³¹

²² “A society that enables people to fulfil their potential no matter what their background or circumstances (including their socio-economic background and circumstances).” Well-being of Future Generations (Wales) Act 2015: the essentials”, Welsh Government, 15/06/2021

²³ Welsh Government (2020), Strategic Equality Plan 2020-2024

²⁴ “There remains an ‘implementation gap’ when it comes to putting innovative social policy into practice”, Nash and Pritchard, Journal of Law and Society, (November 2020), “Administrative Justice in Wales” Nason, Sarah and Pritchard, Huw 2020. Administrative justice in Wales. Journal of Law and Society 47 (S2), S 262-S 281. 10.1111/jols.12273 file

²⁶ Bevan Foundation (February 2021), “Differing Experiences of Poverty in Winter 2020”

²⁷ Office of National Statistics (2020), “Domestic Abuse During the Coronavirus Pandemic, England and Wales: November 2020

²⁸ Focus group targeted towards disabled women

²⁹ Welsh Womens Aid (2021), “COVID 19: One Year On”

³⁰ SafeLives (2017), Disabled Survivors Too Disabled People and Domestic Abuse

³¹ Disability Wales and Welsh Womens Aid (2019), Support Disabled People Experiencing Violence Against Women, Domestic Abuse and Sexual Violence in Wales

Many support services and networks for LGBTQ+ people are not accessible to those living in rural areas of Wales.^{32 33} In our focus groups we have also received concerning reports from disabled LGBTQ+ people about the intersection of transphobia and ableism. During our focus group targeted at LGBTQ+ disabled people it was reported by one person that autistic transgender people especially have been told that they do not understand their gender identity or that their position as autistic individuals has been used to undermine their gender identity, although the focus group attendee did not specify by who, elsewhere autistic transgender individuals have reported being told this by medical staff.^{34 35 36} We noted the inclusion of the experiences of LGBTQ+ disabled people in the WG's LGBTQ+ Action Plan for Wales³⁷ and specific questions on the subject in the consultation document,³⁸ however still more active work must be undertaken to address these issues and the associated ableism.³⁹

Disabled ethnic minorities have also reported some unique barriers and discrimination. One key theme from our focus group targeted towards disabled ethnic minorities was the need to “code switch”⁴⁰ in medical and social care settings, one participant reported that a person's access to both medical and social care can depend on their ability to successfully code-switch into a particular language and behaviours favoured by predominantly White structures, this was consistent with the experiences of others in the focus group.

³² LGBTQ+ Focus Group, (2021)

³³ Joseph Ali, Wales Online (2020), “What it's Really Like Living in Rural Wales as Part of the LGBT Community”

³⁴ LGBTQ+ Focus Group, (November 2021)

³⁵ Emma Robdale, Disability Arts Online (2018), “You're Not Trans... You're Autistic!”

³⁶ “I think there's been some worrying developments where people who are arguing for fewer LGBTQ plus rights specifically against fights for trans non binary people have tried to weaponize disability. So, they've talked about how autistic people, for example, may be coerced or manipulated.” Focus group participant, LGBTQ+ Focus Group (November 2021)

³⁷ Welsh Government, (July 2021), LGBTQ+ Action Plan for Wales

³⁸ Welsh Government, (2021), “Consultation on the LGBTQ+ Action Plan”

³⁹ Ruth Bevan and Anna Laws, University of Hertfordshire, (2019), Gender Dysphoria and People with Intellectual Disability

⁴⁰ Christopher Boulton, Howard Journal of Communications, (2016), Black Identities Inside Advertising: Race Inequality, Code Switching, and Stereotype Threat” How speakers might modify their vocabulary and even shift their “pitch, volume, rhythm, stress, [or] tonal quality” to better accommodate the expectations of their listeners or conform to the context of perceived participant roles and relative power hierarchies of any given social interaction”

When asked specifically about whether the rights of disabled children are successfully implemented, 27/52 respondents to our survey responded negatively.⁴¹ We received significant feedback about issues impacting disabled children. Particularly multiple survey respondents and focus group participants raised concerns about the absence of direct engagement,⁴² which, according to the experience of one survey respondent, has led to the voices of, especially White, educated, parents being listened to over the views of disabled children themselves.⁴³ We also heard about concerning gaps in resources for disabled children, e.g. Guide Dogs Cymru reported that there are no specialist services for visually impaired children in Wales.⁴⁴ In our focus groups parents of disabled children also reported that there are insufficient resources available for supporting their child in other areas of their life.⁴⁵ The impact of high levels of child poverty in Wales was also mentioned as a key concern, according to data from the End Child Poverty Coalition, 31% of children in Wales live in poverty.^{46 47}

Of the 52 respondents to our survey, 1 respondent thought Article 10, ‘the right to life’, is fully respected in Wales.⁴⁸ The impact of the coronavirus pandemic has been significant.⁴⁹ One disabled person responding to our survey told us that they have felt a double threat, from both the virus itself and those supposed to be supporting them.⁵⁰ A key concern was Do Not Resuscitate notices being put on disabled people’s medical files during the pandemic. In the early stages of the pandemic, a GP Practice in Maesteg, South Wales wrote to disabled patients asking them to sign a DNR form, on the grounds of saving medical resources for others, which was mentioned by some respondents to the survey.⁵¹ From the evidence gathered in the Locked-Out report and the fear around DNR notices during the pandemic, we do not believe enough is being done to preserve and value the lives of disabled people in Wales.

⁴¹ Disability Wales survey

⁴² Wales UNCRC Monitoring Group, (December 2020), Wales Civil Society Report to the United Nations Committee on the Rights of the Child to inform their List of Issues Prior to Reporting (LOIPR), p27

⁴³ Those who get a voice are often white, middle class, parents. Cardiff schools not accessible enough. Difficulties with cultural access.” One survey respondent

⁴⁴ Guide Dogs Wales, “State of Children’s Rights in Wales”, email submitted to Disability Wales as advice.

⁴⁵ One parent of disabled child in LGBTQ+ Focus Group, (November 2021)

⁴⁶ “Although Welsh Gov have tried to mitigate, high levels of children poverty and poor access to CAHMS services result in poor results for disabled children.” Survey respondent

⁴⁷ Bevan Foundation, (May 2021),” New data published by the End Child Poverty Coalition highlights extent of child poverty in Wales

⁴⁸ Disability Wales survey

⁴⁹ Welsh Government, July 2021 Locked out: liberating disabled people’s lives and rights in Wales beyond COVID-19 report

⁵⁰ “The Covid-19 pandemic has shown us how little our right to life is valued. We have felt physically threatened by both the disease and those supposed to be there to look after us”, Disability Wales survey respondent

⁵¹ BBC, (2020), “Coronavirus: GP surgery apology over ‘do not resuscitate’ form”

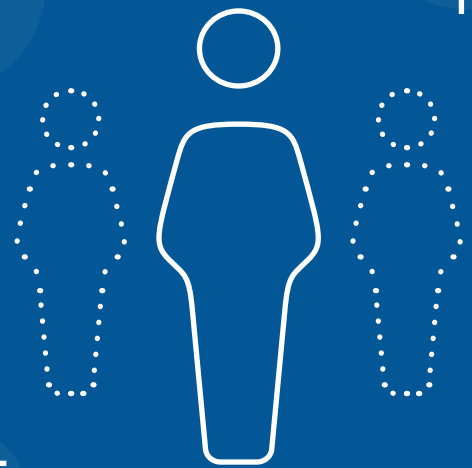
Recommendations:

We recommend that the committee ask:

1. What measures are the WG taking to close the implementation gap between policy intentions aimed at achieving disability rights and equality and provision of services that do not deliver this?
2. What measures will be put into place to ensure that the right to life of disabled people is respected in healthcare settings? What is being done to ensure that what happened in Maesteg will never reoccur?
3. Ask what is being done to support disabled people with multiple marginalised identities.
4. Ask why there are no specialist services for visually impaired children in Wales, are the WG consulting with visually impaired children and their parents on this issue? Are there any future plans for these services?

Section Three

Independent Living and Equal Access



Section Three

Independent Living and Equal Access

One of the key issues raised by disabled people who we spoke to in the focus groups and responded to our survey was their ability to live independently in the community. Public transport has been repeatedly raised as a major limitation on independent living, especially for those living in North Wales or in rural areas.^{52 53} This has been reported to us as a major barrier to Articles 19 and 20. As one disabled people told us, even if they are able to access local urban centres, the design of the centres themselves and the buildings are often inaccessible.⁵⁴ LGBTQ+ disabled people, in particular, have raised concerns about their ability to access LGBTQ+ support services and community venues e.g., LGBTQ+ nightclubs.⁵⁵

In our survey, some respondents told us that they do not believe that the right to Home and Family life is effectively implemented in Wales. There has been reported incidents of disabled people being unable to choose where they live and having to move away from loved ones and support networks.^{56 57} One disabled person responding to our survey reported that, after refusing to move away from their support network, they had been threatened with a court order to force them into the accommodation.⁵⁸ Several disabled people living in institutions and assisted living facilities in Wales have told us that they have been disallowed from engaging in romantic relationships.⁵⁹ This is a common problem for disabled people with a learning

⁵² North Wales Focus Group, (November 2021)

⁵³ Prior and Rees, EHRC, (December 2020), "Accessible Public Transport for Older and Disabled People in Wales"

⁵⁴ One Disability Wales survey respondent

⁵⁵ "I know for a fact I wouldn't be able to get into half of the LGBT venues within Cardiff because they're not suitable or there are no ramps or the venues underground.", LGBTQ+ Focus group participant, (November 2021)

⁵⁶ Equality and Human Rights Commission, Housing and Disabled People Wales's Hidden Crisis, (May 2018, p8)

⁵⁷ Megan Thomas, Disability Wales, Bring Us Our Rights Disabled People's Manifesto, (December 2020, p14)

⁵⁸ One survey respondent "I have experienced the threat of being placed against my will into residential accommodation 50 miles from any friends as there wasn't anywhere available locally. When I expressed my dismay at this I was told that a court order could be made to force me to accept this accommodation."

⁵⁹ Survey respondent, "Relationships are discouraged and when someone has a partner housing providers rules stop people from staying over."

impairment specifically, many of whom have been prevented from entering romantic relationships either by lack of resources, for example, places to spend time with a partner, or from attitudes of members of staff. A lack of access to sex education and lack of support for LGBTQ+ individuals has also been highlighted by advocacy organisations.^{60 61}

There are significant barriers to disabled people accessing education in Wales.^{62 63} Disabled students responded to our survey reporting significant accessibility barriers in education, such as insufficient support for D/deaf students and inaccessible physical spaces.^{64 65} A student with a learning disability reported being limited in the choice of courses they can take due to access options.⁶⁶ A survey respondent told us that, when they asked to be able to undertake training later in life, they were told "no as you would never work."⁶⁷ Education is vital, not just for disabled people but for all, as one disabled person told us: children in classrooms that are educated in disability rights and equality become adults who understand their importance.⁶⁸ In 2020 the Children's Commissioner for Wales set out numerous ways in which the coronavirus pandemic both created additional barriers for education and helped address some of the issues being faced by disabled children previously.⁶⁹

We have heard reports of several issues that impact disabled people's access to their article 27 right to work and employment. A key issue repeated in the survey responses and by individuals in focus groups was reluctance by employers to implement their reasonable adjustments.^{70 71} Lack of Legal aid is a key factor here, as disabled people

⁶⁰ Simon Richards, All Wales Peoples First, Position Statement on Sexual Relationships, (04/09/2019)

⁶¹ Naomi Harflett and Sue Turner, National Development Team for Inclusion, Supporting People with Learning Disabilities to Develop Sexual and Romantic Relationships, (June 2016, p8)

⁶² UNCRDP and Disability Rights in Wales Review Launch Focus group participant, "Children are different, but he's learned that school, it's not a good place to be", (02/11/2021)

⁶³ Welsh Government, Planning to Increase Access to Schools for Disabled Pupils, (March 2018, p2-10)

⁶⁴ One Disability Wales survey respondent

⁶⁵ Wales UNCRC Monitoring Group, (December 2020), Wales Civil Society Report to the United Nations Committee on the Rights of the Child to inform their List of Issues Prior to Reporting (LOIPR)

⁶⁶ One Disability Wales survey respondent

⁶⁷ One Disability Wales survey respondent

⁶⁸ Because if we do, and we get it, right, and the adults who were in school, understand about bias and stigma and discrimination, properly understand, [...] if you get it right with your future generation of social workers, nurses, doctors [...] it will be more instinctive to them." UNCRDP and Disability Rights in Wales Review Launch Focus group participant

⁶⁹ Childrens Commissioner for Wales, Coronavirus and Me: Understanding How Disabled Children and Young People Have Experienced the Pandemic in Wales, (2020, p18-20)

⁷⁰ "Some organisations refuse to make reasonable adjustments", one Disability Wales survey respondent

⁷¹ Wales TUC Cymru, (2018), "Disability and 'Hidden' Impairments in the Workplace A Wales TUC Cymru Report"

have difficulty being able to benefit from legislation that currently exists as many do not have the resources to navigate a tribunal process.^{72 73 74}

Disabled people have reported significant problems in accessing healthcare in Wales, the 40/52 respondents to our survey did not believe that their rights were fully respected in healthcare.⁷⁵ The 2021 ‘Locked Out Report’ on the experiences of disabled people during the coronavirus pandemic reported that decisions on how NHS resources are allocated reflect “dominant social values and priorities”, resulting in disabled people feeling neither valued or priority.⁷⁶ One survey respondent, speaking on behalf of themselves and others, told us that the coronavirus pandemic has resulted in significant access issues to services, exacerbated by the move to on-line and telephone-based service provision by some providers.^{77 78}

In both the focus groups and in responses to our survey, disabled people reported that medical professionals often view them negatively, disregard their experiences of their own bodies, and cannot accept that disabled people can have an excellent quality of life. In the survey and focus groups we did not have any disabled people give any positive experiences.⁷⁹ The Welsh model of seven health boards can result in difficulties for patients who require access to specialized treatments as often patients in one health board are unable to or have difficulty accessing a service in another.^{80 81 82}

⁷² One Disability Wales survey respondent

⁷³ Megan Thomas, Disability Wales, Bring Us Our Rights Disabled People’s Manifesto, (December 2020, p14)

⁷⁴ Welsh Government, July 2021 Locked out: liberating disabled people’s lives and rights in Wales beyond COVID-19 report

⁷⁵ Disability Wales Survey

⁷⁶ “Decisions about the allocation of scarce NHS resources are essentially political and reflect dominant social values and priorities. Disabled people told us that during the pandemic they felt neither valued, or a priority.”

⁷⁷ Welsh Government, July 2021 Locked out: liberating disabled people’s lives and rights in Wales beyond COVID-19 report

⁷⁸ “Poorer services, as people less comfortable speaking over the phone as in person.” One Disability Wales survey respondent

⁷⁹ Honeyman M, Maguire D, Evans H and Davies A. (2020), Public Health Wales NHS Trust, “Digital technology and health inequalities: a scoping review (2020)”

⁸⁰ “The medical profession tend to view us very negatively, they cannot accept that a disabled person can have an excellent quality of life, they just see the negatives of us being “not normal”... My views were totally disregarded, my experience of my body counts for nothing apparently.” One Disability Wales survey respondent

⁸¹ Royal College of Physicians, Ending the Postcode Lottery, (November 2021)

⁸² Fair Treatment for Women in Wales, “FTWW Manifesto for 2021 Make Womens Health a Priority for Wales”, (2021)

⁸³ “Wales’s system of seven autonomous health boards means that where services aren’t available in the locality, patients can often be prevented from accessing them”, FTWW response to Disability Wales.

Women’s groups have raised concerns that the cultural taboo around areas of healthcare that primarily affect women^{83 84} which results in a lack of communication, research, and education in these areas.⁸⁵

We are concerned about the poor implementation of Article 28 in Wales. There are significant barriers to disabled people being able to live their lives as they would choose. The damage to the UK welfare system from years of austerity policies enforced by WeG have been well documented and acknowledged by the UN itself.^{86 87}

Poverty is an overwhelming barrier, one survey respondent described poverty as a “fact for disabled people in Wales”.⁸⁸ Much of this is reserved to WeG, but some benefits are distributed by local authorities and are therefore under the competency of the WG, such as direct payments⁸⁹ and local housing allowance (LHA).⁹⁰ The WG have set out clear plans to improve these services and an ambition, shared with many disabled people,⁹¹ that these must be used to support disabled people access independent living, however, for some of the disabled people who responded to

⁸³ “Wales’s system of seven autonomous health boards means that where services aren’t available in the locality, patients can often be prevented from accessing them”, FTWW response to Disability Wales.

⁸³ “The culturally ‘taboo’ nature of many women’s health conditions is disabling, so too are the multifarious impacts of those attitudes. Common gynaecological conditions (such as heavy menstrual bleeding, endometriosis and adenomyosis, menopause) aren’t made the topic of Public Health or educational campaigns, so there is little publicly and widely available information from a trusted source available to this population. This results in delayed diagnosis and a lack of support from family, friends, or employers. Unfortunately, a widespread reliance on the medical model to access benefits and / or reasonable adjustments in the workplace results in many disabled women / women living with long-term health conditions being denied their rights. Lack of research, lack of diagnosis, and a lack of ‘seriousness’ attributed to women’s health has knock-on effects for provision of health services in Wales: many of the conditions which predominantly affect females are not prioritised for investment, resulting in a widespread lack of access to suitably expert care and rendering many women disabled as a result. Health conditions particularly affected include ‘benign’ gynaecology, autoimmune diseases, hypermobility syndromes, energy-limiting and chronic pain conditions, and Long Covid. Female neurodivergence, whilst not a health condition in itself, is associated with various comorbidities and yet there is a widespread lack of recognition or support available to this population. Due to prejudicial assumptions about how neurodivergence ‘presents’, many autistic females are not diagnosed before middle age and often have to turn to private clinicians for their diagnosis. Limited guidance and poor oversight of ‘shared care agreements’ then means that they will be denied local care as a result of obtaining their diagnosis privately – even when those practitioners also work in the NHS.” FTWW response to Disability Wales

⁸⁵ “Race Equality First, ”Race Equality First’s Written Submission to the UNCRDP Call for Evidence”, received November 2021.

⁸⁶ Disability Benefits Consortium, *How Welfare Became Unfair*, (2019)

⁸⁷ OHCHR, (November 2018), “Statement on Visit to the United Kingdom, by Professor Philip Alston, United Nations Special Rapporteur on extreme poverty and human rights”

⁸⁸ “Poverty is a fact for disabled people in Wales, but it is because benefits are set by UK government not Welsh, I’m living on the equivalent of £3 hr!” One Disability Wales survey respondent

⁸⁹ Citizens Advice, “Using Direct Payments for Care”

⁹⁰ Welsh Government, (March 2019), “Local Housing Allowance”

⁹¹ Welsh Government, (2014), *Social Services and Wellbeing (Wales) Act 2014*

our survey and attended our focus groups, these ambitions have not been realised. Disabled people report persistent difficulties accessing the social care support that works best for them, whether that is becoming an employer and getting the flexibility of direct payments or the more rigid but less admin-heavy agency work.⁹²

Access to appropriate housing is a key concern for many disabled people in Wales. Housing organisations in Wales have raised concerns about insufficient quality social housing being built in Wales,^{93 94 95} 67% of respondents to a survey conducted by the Bevan Foundation supported building more social housing.⁹⁶ One disabled person who lives in private rented accommodation told us about experiencing discrimination from landlords.⁹⁷

For disabled people who seek to engage in public and political life, there have been some positive improvements. The WG Access to Elected Office Fund⁹⁸ established in 2021, in which financial compensation for impairment-related costs is provided to disabled political candidates, has had positive feedback from several disabled people responding to our survey.⁹⁹ However, one area to address is that many blind and partially sighted people are unable to vote in secret and that the process must be improved to allow them to vote independently.^{100 101}

⁹² “The evidence gathered by this project suggests that co-production needs to be better understood and that further work is needed to explore how it, and the values that underpin it, can be better embedded in people’s interactions with social care. Negative stories raised issues of the need to fight for services, of feeling judged when accessing care and support, and of needing to fit in with service provision no matter how inconvenient. Marked by a lack of connection, these stories revealed experiences of lives made more complicated by care, of declines in mental health and of individuals who were resigned to the hard work, frustration and occasional indignity of needing support.” Katie Cooke, Rachel Iredale, Richard Williams, Neil Wooding (2019), University of South Wales, *Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales*

⁹³ Simon Hoffman, Tai Pawb, (June 2019), The Chartered Institute of Housing Cymru and Shelter Cymru, *The Right to Adequate Housing in Wales: Feasibility Report*

⁹⁴ Mike Hedges MS, Bevan Foundation, “Build Build Build”, (February 2022)

⁹⁵ Rob Simkins, Shelter Cymru, (December 2020), “Politicians Have Listened to Our Social Housing Campaign. Now its Time for them to Take Action”

⁹⁶ Bevan Foundation, *A Snapshot of Poverty in Winter 2021*, (December 2021)

⁹⁷ “Lack of appropriate housing is very much an issue for me as a disabled person with visual and mobility issues who is currently living in a 2 storey house where a bungalow or ground floor flat would be more appropriate. Unfortunately there is very little appropriate housing stock where I live. I also experience discrimination from my landlord, who quite often says things such as “I know you’re visually impaired but missing that dust on the skirting boards whilst cleaning is unacceptable”” One Disability Wales survey respondent

⁹⁸ Disability Wales, “Access to Elected Office Fund Wales”

⁹⁹ Disability Wales survey

¹⁰⁰ “The voting process needs to be improved so that blind and partially sighted voters can vote independently and in secret, as is the right of every other voter” One Disability Wales Survey respondent

¹⁰¹ Letter from RNIB Cymru Direct to Members of the Equality and Social Justice Committee

Research conducted by Disability Arts Cymru revealed significant barriers for disabled artists, including inaccessible processes for grant applications, and barriers arising from socio-economic background or class.¹⁰² One disabled artist responding to our survey set out that they have difficulty accessing funding as a disability-led arts group.¹⁰³

Recommendations:

We recommend that the committee ask:

1. Since the publication of Action on Disability: A Framework for Independent Living, what improvements have been made for disabled people accessing public services?
2. Why hasn't more accessible social housing been built in Wales and what plans do WG have to address this?
3. What is being done to improve public transport in Wales? Why is there still persistent issues with access to public transport, especially in North Wales?
4. What is being done to combat negative attitudes to disabled people in healthcare in Wales? What measures are in place to mitigate issues or support disabled people who have experienced discrimination in healthcare settings?
5. What progress is the Welsh Government making towards the development of a women's health strategy?
6. What steps are being made to support disabled people being able to vote independently and in person in Welsh elections?
7. What steps are being made to improve access to cultural life, recreation and sport in Wales?

¹⁰² Disability Arts Cymru, (December 2021), "Bring Us Our Creative Rights", <https://static1.squarespace.com/static/6027a7fc2fb17600e9e59d61/t/61aa02902e51f37b6d33f808/1638531734822/DAC-Manifesto-2021.pdf>

¹⁰³ "I am a disabled artist and help run a disabled-led art group and there is not enough statutory funding specifically for disability artists. Elite disability sport gets funding but not grassroots opportunities for sport. Public transport and lack of funding for personal support restrict people's ability to take part in culture, sport and leisure." One Disability Wales survey respondent

Conclusion

Throughout this report, we have seen a gap between the experiences of disabled people and the intentions of those in power. This report aims to highlight the experiences of disabled people in Wales as well as progress with bridging this gap. Although we have seen some positive steps since 2017, the next challenge is to implement the rights of disabled people fully in Wales in the wake of the pandemic and the impending cost of living crisis.

List of Appendixes

Appendix One: List of reserved powers

Appendix Two: Locked out: Liberating disabled people's lives and rights beyond COVID-19

Appendix Three: Bring Us Our Creative Rights



Disability Wales
Anabledd Cymru