

Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee on the Rights of Disabled People under article 6 of the Optional Protocol to the Convention

# Alternative report from civil society

August 2023

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# Abbreviations

ADP	Adult Disability Payment
AtW	Access to Work
CQC	Care Quality Commission
CAMHS	Children and Adolescent Mental Health Services
CRDP	Convention on the Rights of Disabled People
CYP	Children and Young People
DATS	Disability Action Transport Services [Northern Ireland]
DDP	Deaf and Disabled People
DfC	Department for Communities [Northern Ireland]
DHSC	Department for Health and Social Care [Westminster]
DfI	Department for Infrastructure [Northern Ireland]
DLA	Disability Living Allowance
DNACPR	Do Not Attempt Cardio-Pulmonary Resuscitation
DSA	Disabled Students Allowance
DWP	Department for Work and Pensions [Westminster]
EHCP	Education, Health and Care Plan
EHRC	Equality and Human Rights Commission [England and Wales]
ESA	Employment and Support Allowance
EU	European Union
FGM	Female Genital Mutilation
FSM	Free School Meal
ILFS	Independent Living Fund Scotland
IPR	Internal Process Review

IWP	In-Work Progression
JR	Judicial Review
LA	Local Authority
LASPO	Legal Aid, Sentencing and Punishment of Offenders Act
LCW	Limited Capability for Work
LCWRA	Limited Capability for Work Related Activity
MAC	Migration Advisory Committee
MR	Mandatory Reconsideration
NAO	National Audit Office
NDS	National Disability Strategy
NHRI	National Human Rights Instrument
NI	Northern Ireland
PA	Personal Assistant
PEEP	Personal Emergency Evacuation Plan
PIP	Personal Independence Payment
ppt	percentage points
SDS	Self Directed Support
SG	Scottish Government
SEND	Special Educational Needs and Disability
SSS	Social Security Scotland
TUC	Trades Union Congress
WEC	Women and Equalities [Parliamentary] Committee [Westminster]
WG	Welsh Government
WeG	Westminster Government
WPSC	Work and Pensions [Parliamentary] Select Committee [Westminster]

WRAG      Work Related Activity Group  
UC         Universal Credit  
VAWG     Violence Against Women and Girls

# Explanatory Note

This is the report that was sent as a written submission to the special inquiry follow up carried out by the United Nations Committee responsible for the Convention on the Rights of Disabled People.

It is a UK wide report.

There have been many significant developments since the findings from the special inquiry investigation were published in November 2016.

As such there were a considerable number of issues to include. These all had to be backed up with evidence.

In the copy of the report sent in to the Committee we made greater use of footnotes under the main text and of appendices and annexes at the end of the report. This meant we could meet the word limit for the report, provide extra detail and evidence for those with the time and interest and also give a clear narrative within the main body of the report for those with less time.

In this version of the report, we have moved some of the detailed information into the main body of the report to make it more accessible.

We appreciate the importance that the Convention has to Deaf and disabled people. We also understand how serious the issues in this report are and the very direct impact they have on people's lives. We thought therefore that many readers would want access to that more detailed information but in a way that is easier to read.

# Summary

## 1. Introduction

This report provides information on the implementation of Articles 19, 27 and 28 by the UK Government (UKG) since publication in November 2016 of the findings and recommendations from the Committee’s inquiry under article 6 of the Optional Protocol to the Convention on the Rights of Disabled People.

This report has been compiled by Deaf and Disabled People’s Organisations (DDPOs) in England, Wales, Scotland and Northern Ireland (Ni).

DDPOs are organisations run and controlled by Deaf and Disabled people (DDP).

DDPOs follow the social model of disability and the cultural model of Deafness. These are consistent with a human rights model.

Readers are reminded of the devolution framework in the UK.

Where an issue is a “reserved” one, legislation and policy set by the Westminster Government (WeG) can apply to all 4 nations in the UK or to Great Britain (England, Scotland and Wales) or to England and Wales.

Where an issue is “devolved” it is the responsibility of the national governments in Northern Ireland (Ni), Scotland (SG) and Wales (WG). WeG also functions as the national government of England.

Some measures the devolved governments have introduced either to mitigate against the harmful impacts of legislation and policy set by WeG on reserved issues, or to take progressive action in the absence of any from WeG. DDP in England do not have these protections.

Responsibility for social care support in England is devolved by WeG to local authorities (LAs) and the devolved nations.

Northern Ireland is facing a significant political and economic crisis in which severe budget cuts are negatively impacting on DDP.

Decisions to cut funding are being taken by senior civil servants with no accountability. The removal and deep cuts to services will have a disproportionate cumulative impact on DDP.

We would argue that there are ongoing violations of DDP's rights due to welfare reform, austerity and now also the political crisis in Northern Ireland. There are around 410,000 DDP in NI.

DDP experience extra barriers if we have additional protected characteristics and are subject to multiple forms of oppression.

Intersectionality is routinely overlooked in policy planning which heightens the levels of risk that DDP are exposed to.

## **2. Over-view since 2016**

UK DDP/DDPOs are overwhelmingly of the view that the Committee's recommendations have not been implemented.

WeG continues not to monitor article 19 rights. It delegates away responsibility for meeting these with no system for accountability. In England, the situation has deteriorated dramatically further since 2016.

Barriers to good work for DDP have increased since 2016 (article 27). This disproportionately impacts on Deaf and disabled workers. WeG's priority is to get DDP out of the social security system whether they have a living income or not.

WeG's new social security proposals (article 28), and the accompanying political and media rhetoric are in direct contravention of the special inquiry recommendations.

Evidence of further continued and significant retrogression is particularly stark in relation to those areas covered by the special inquiry.

## **Independent living**

Support to live in the community is devolved. However, this is within the context of austerity and welfare reform enforced by WeG across the UK since 2010.

There are significant barriers to and retrogression of rights to independent living across the UK affecting around 1.2 million DDP who use social care support services.

The situation regarding support available for DDP to live in the community varies between the different nations.

WeG closed the Independent Living Fund (ILF) from the end of June 2015. At the time of closure there were 18,000 recipients across the UK.

Mental health legislation continues to authorise substitute decision-making, detention in psychiatric institutions, involuntary treatment and the use of community treatment orders.

WeG continues to have in place its reservation and interpretative declaration on CRDP article 24 and in investing in building new special schools.

## **Employment**

The number of DDP in employment has increased since 2016.

The number of “economically inactive” DDP rose by 273,000 between 2022 and 2023 while the numbers of unemployed DDP remained the same.

Northern Ireland, the North East of England, Scotland and Wales have the highest disability employment gaps.

Difficulties accessing WeG's Access to Work disability employment support programme have not eased. A backlog of 20,909 AtW cases awaiting decisions on applications were reported in 2022.

In January 2023 it was reported that lengthy delays, often as long as half a year, for applications and claims were putting thousands of DDP jobs at risk

Other examples of increasing barriers to employment include increasing disability discrimination within the workplace, intensification of labour and the rise of "bad" work with increasing job insecurity and jobs without protections such as statutory sick pay.

Higher number of DDP in work is no guarantee they are in suitable work or work that provides a living income.

DDP are over-represented among those on low pay.

The disability pay gap has widened.

Seven in 10 (69%) disabled workers earn less than £15ph compared to half of non-disabled workers (50%).

DDP are over-represented among workers on zero hours contracts.

Intersectional discrimination with regards to disability employment and pay gaps affects workers who belong also to other protected characteristics.

Disabled women workers are more likely to experience sexual harassment in the workplace than non-disabled women workers.

Anecdotally we have heard about increasing disability discrimination in the workplace and failure by employers to put in reasonable adjustments.

We have also heard about how poverty acts to move DDP further from employment.

## Social and security and poverty

7.2 million people in households with a disabled member are living in poverty. This accounts for half of all UK poverty.

DDP are almost three times as likely to live in material deprivation than the rest of the population.

One-in-three adults in the lowest household income decile are disabled, compared to fewer than one-in-ten of adults in the highest household income decile.

Analysis of the cumulative impact of tax and welfare reform since 2010 commissioned by the Equality and Human Rights Commission (EHRC) shows DDP as among the biggest losers. The more disability within a household, the higher the annual cash loss.

Benefits in the UK are comparatively low by international standards with one of the lowest benefit rates relative to earnings.

The real terms value of the standard benefit payment is £40 per month (or 11%) lower than it was in 2010.

Use of foodbanks and homelessness have both increased amongst DDP.

The four year benefit freeze (2016 – 2020) affected 27 million people while sweeping another 400,000 into poverty.

WeG expected roughly half of the households who would lose from the benefit cap to contain someone who is disabled.

After the benefit cap was lowered more than 10,000 households that included a disabled adult had their benefits cut.

Substantial numbers of DDP have lost income through the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP).

Figures published in June 2018 showed that since the roll-out of PIP, 381,640 disabled people who previously received DLA had been turned down for the new benefit upon reassessment.

As of January 2020, 102,000 Motability customers had lost PIP awards that entitled them to vehicles to facilitate travel and mobility.

In December 2017, the High Court ruled that changes to the PIP regulations brought in by the UKG in an attempt to restrict eligibility to people living with psychological distress, were “blatantly discriminatory”.

WeG reduced benefit payments for DDP in receipt of Employment Support Allowance (ESA) placed in the “Work Related Activity Group” (WRAG) following a Work Capability Assessment (WCA) in spite of widespread opposition from DDPOs, charities, MPs and members of the House of Lords.

As of May 2016, there were 429,000 in the WRAG.

The £30 per week cut – equivalent to nearly one third of the benefit – applied to new ESA and UC claimants from April 2017.

Even before the cut, research had shown that 28% of claimants in the WRAG could not afford to eat.

WeG pushed on with the roll out of Universal Credit (UC) despite extensive evidence of adverse impacts, hardship caused by its introduction and concerns that household rather than individual claims would trap women in abusive relationships.

Concerns raised by the UN Extreme Poverty Rapporteur were dismissed.

We are not aware of any equality impact assessment carried out for the decision to design UC as digital by default, which excludes significant numbers of disabled DDP.

DWP has ignored calls for automatic enrolment onto UC of existing benefit claimants. DDPOs and charities have warned that thousands are at risk of destitution because they do not have the skills or support to apply for and maintain a UC claim.

A legal challenge taken by two disabled men who had lost £180 per month after being moved to UC won compensation for others similarly affected but there remains no Severe Disability Payment/Enhanced Disability Payment for new claimants.

Benefits assessments introduced after 2010 continue to cause widespread distress among DDP, stress on our families/support networks and strain on support services. The issues are the same that we have been reporting for over a decade.

The scale of impact that these assessments have is considerable: as of February 2022 there were 1.7 million people claiming ESA and 3.8 million people claiming either PIP or DLA.

DDP live in constant anxiety about being called up for reassessment. This has a detrimental impact on people's mental health.

Reassessment puts DDP under threat of having all or a substantial part of our income stopped. DDP unable to navigate the complex assessment process and without support are put in situations of high risk.

In 2013 the high court ruled that the WCA discriminates against people living with mental distress by requiring them to collect and send off their own evidence when this might not be something they are able to do. The burden of evidence still lies with the claimant.

The quality of assessment reports has been a constant issue since they were introduced. WPSC found evidence of "systematic poor quality".

The rate of assessment decisions over-turned at appeal stood at 75% for both ESA and PIP in quarterly statistics for June – April 2019.

Despite this, WeG does not accept a safeguarding duty for benefit claimants. They have continuously declined to call for an inquiry into benefit-related deaths.

Deliberate gaps in published data under UC make it more difficult to understand the current situation.

In 2013, WeG introduced an additional stage to the assessment process called “Mandatory Reconsideration”.

The majority of MRs rubber stamp the original decision.

The introduction of MR has undoubtedly discouraged claimants to go to appeal. In 2020, the High Court ruled that forcing claimants to go through MR for ESA was unlawful. It remains in place for PIP.

Of 3,500 survey respondents, 13 per cent said they had attempted suicide as a result of interacting with the DWP. A third said it had caused them to plan suicide, while 61 per cent said the way the system is implemented led them to have suicidal thoughts.

Nothing has been done to bring benefit assessments in line with a human rights approach.

Deaths and suicides linked to benefit changes continue to happen.

Investigations of case handling that may have resulted in serious harm more than doubled in the three years from July 2019.

There is credible evidence of a culture of hostility towards benefit claimants within DWP.

Benefit sanctions are proven to discriminate against DDP and cause considerable avoidable harm.

Research has shown that disabled job seekers were 26 – 53% more likely to receive a sanction than non-disabled job seekers.

Sanctions have been linked to the deaths of disabled claimants and to increased foodbank use.

DWP staff have reported pressure from managers to apply sanctions.

In March 2023 the Chancellor announced an intensification of the conditionality regime.

According to DWP statistics, DDP exit the social security system onto no recorded income at double the rate without sanction.

WeG now proposes to end the Work Capability Assessment (WCA). Instead, both out-of-work and extra costs disability benefits will depend upon the one PIP assessment.

PIP assessments are not designed to test for work capability.

The same problems with the WCA are associated with PIP assessments.

With just one assessment, DDP found ineligible will lose both benefits at once.

Currently 632,000 DDP get out-of-work disability benefits but not PIP.

Claimants who get PIP will get a new UC “health element”.

There will no longer be a category of benefit that automatically exempts those in it from conditionality and sanctions.

Work coaches will decide what level of work-related activity each individual claimant.

DDP/DDPOs are concerned that work coaches are not equipped to make these decisions even with more training.

In-work progression will be mandatory from September 2023, affecting around 600,000 claimants in total.

When fully rolled out, it will affect 1.2 million of which 27% are DDP.

Once they are migrated to UC we will not be able to see if DDP are being discriminated against by this policy as no disaggregated data on sanctions is kept under UC.

### **Mitigating measures**

Various mitigating measures have been adopted by the respective governments to lessen the harmful impacts of the austerity and welfare reform measures implemented by WeG.

In Scotland, there are concerns that human rights rhetoric is not always implemented in practice.

Time taken to process Adult Disability Payment (ADP) and Child Disability Payment has increased and processing times vary from a few weeks to over six months in more complex cases.

In Wales, *Action on Disability: Framework for Independent Living* is an action plan aimed at reducing or removing social barriers to equality experienced by disabled people.

The Socio-economic Duty, established in 2020, requires all public bodies in Wales to consider the impact on those with socio-economic disadvantage in all their activities.

## 3. New Issues

### EU withdrawal

EU withdrawal followed by the pandemic has dramatically exacerbated the recruitment crisis in social care.

In adult social care in England as at 2021/22 there were 165,000 vacant posts, up 55,000 or 52% since 2020/1.

Disabled people living in their own homes now face even greater barriers to recruiting Personal Assistants (PAs).

DDP living in the community and acting as individual employers for Personal Assistants (PA) were not included in pre-Brexit preparations.

WeG has directly allocated replacement EU funding at a dramatically diminished level for Wales.

European Social Fund (ESF) has been the primary source of funding for employment projects for DDP in NI. The funding will cease in March 2022.

### COVID-19

Disability inequality was becoming entrenched before the pandemic. The impacts of the pandemic both exacerbated and were exacerbated by that existing inequality.

WeG was not prepared for the pandemic. WeG did not engage with DDP or DDPOs when formulating their response, despite DDP being both most at risk from COVID-19 and worst impacted by measures adopted to contain the pandemic.

The intersectional needs of DDP were not considered. For example, Disabled asylum seekers were overlooked except for community initiatives.

Disabled people were over-represented among COVID-related deaths, even accounting for age and health factors. Analysis identifies poverty as a key factor within this as well as care home residency.

Official figures record that disabled people accounted for nearly 60% of COVID-related deaths. The true proportion is likely to be higher.

The Coronavirus Act 2020 introduced easements to the duties of LAs towards DDP.

Under the Act, people detained under the Mental Health Act were exempt from the right to go outside for exercise once a day.

The Coronavirus Act also introduced an easement to the Children and Families Act 2014.

Disabled workers were over-represented among redundancies during the pandemic.

DDP faced long delays following requests adjustments and a range of other issues with Access to Work after home working began during lockdown.

Workers experiencing Long Covid have faced employment discrimination. One in seven survey respondents lost their job because of reasons connected to Long Covid.

In March 2020, WeG introduced a temporary pandemic lift to UC of £20 per week. This was not applied to over 2.2 million legacy benefit claimants, three quarters of whom are DDP.

Many of these had significantly increased expenditures due to COVID-19.

The explanation was that the uplift was for people who work. This fuelled a view among DDP that WeG does not value their lives.

Even after the uplift, UC represented just 43.4% of the minimum income required for a decent standard of living. WeG removed the uplift on 30 September 2021, despite widespread opposition.

### **Cost of Living Crisis**

DDP are disproportionately impacted by this as we are people more likely to live in poverty with no savings.

The unavoidable extra costs of disability have increased dramatically in recent years.

DDP have an available amount to spend that is about 44% lower than that of other working-age adults, exposing them hugely to the rising cost of essentials.

DDPOs and charities have criticised government measures to help those on benefits as inadequate.

The political crisis has halted the development of the Anti-Poverty Strategy in NI.

## **4. Devolved Issues**

### **Access to Justice**

In Northern Ireland Barriers exist with respect to reporting crime, and accessing legal advice and legal representation.

In Scotland, DDP are more likely to say they have experienced a civil law problem, but there are still barriers to getting advice

### **Cost of Living Crisis**

In England, a quarter of DDP responding to a cost of living survey have had to use a food bank or have relied on others to get food.

In Northern Ireland, the escalating cost of living emergency has increased the abuse and exploitation of DDP who have been subject to cuckooing and exploitation for access to medication.

78% of DDP not in receipt of disability social security benefits come from households experiencing the highest levels of deprivation.

Despite the Scottish Government uprating all Scottish benefits in line with inflation for 2023-24, they remain inadequate and need to be further increased to address the rising cost of living which disproportionately impacts upon DDP who face additional impairment related costs.

In a survey of DDP, over 75% of respondents reported that they were 'going without or cutting back' on essentials like food, heating and energy, as well as medication and personal hygiene items.

The cost of living crisis is also having consequences for DDP's right to live in a home of their choosing.

The Scottish Government continues to take measures to mitigate the impact of the benefit cap, including through increasing funding for discretionary housing payments, but their mitigating measures for the cost of living crisis are inadequate.

In Wales, poverty is an overwhelming barrier.

Most policy interventions in Wales have been in the form of short-term economic support.

## **COVID-19**

A medical approach to disability determined whether DDP lived or died during the pandemic.

WeG declined to provide national guidance that would guarantee DDP the same rights to life sustaining treatment as non-DDP.

An independent inquiry was commissioned into unlawful use of Unlawful use of blanket Do Not Attempt Cardio-Pulmonary Resuscitation Orders (DNACPRs) on the medical notes of DDP.

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The government only published COVID guidance for DDP on direct payments who employ their own PA's – a group of around 70,000 DDP in England – more than five weeks after it had published guidance for the wider social care sector and only as the result of lobbying by those affected.

Many direct payment users were unable to access personal protective equipment in the early months of the pandemic.

During the pandemic, social care support was reduced or suspended.

Many PAs could not go to work in DDP's own homes because of lack of access to PPE or because they were self-isolating.

Support services for CYP and their families stopped or reduced during the pandemic and were slow to return.

Legal protections for Disabled workers ended on 31 March 2021 when WeG announced an official end to shielding despite COVID rates still being high.

Official communications about the pandemic were confusing and not made available in accessible formats.

In Northern Ireland, the degree to which the emergency response of the Executive to the Covid-19 crisis included people with disabilities and addressed

their needs has been called into question by DDP and by the Equality Commission.

Initial Scottish Government guidance for doctors making treatment decisions during the pandemic was based on blanket approaches to age, medical conditions or disability was discriminatory.

Cuts to social care during the pandemic were devastating for DDP. Despite being three years on from the start of the pandemic not everyone's social care package has been returned to pre-pandemic levels.

The pandemic has had a devastating impact on DDP's mental health.

Social isolation continues to be an issue for DDP left behind as Covid-19 protections have been lifted, with some DDP and their immediate carers effectively still shielding, without the support that was previously available such as universal testing, and community-based support.

There is growing evidence that the Covid-19 crisis has pushed more families into poverty.

Following the publication of the Locked-Out report, which heavily criticised the Welsh Government's response to the coronavirus pandemic, a Disability Rights Taskforce has been established.

Unlike in England for the Care Act 2014, there were no given requirements to not breach the European Convention on Human Rights in this legislation.

## **Disability Narratives and Hate Crime**

Disability hate crime in London soared by 20% in 2019/2020 with around half classified as violence.

In evidence submitted for our 2022 CRDP shadow report we heard anecdotally about stereotypes of DDP as "frauds" now pervading workplaces and associated

bullying by managers and colleagues of DDP when needing/asking for reasonable adjustments.

Disability hate crime has increased by 16% in 2020/2021, according to the Police Service Northern Ireland (PSNI).

## **Employment**

A 2017 report commissioned by Inclusion London found that bureaucratic incompetence and obstructionism had caused the Access to Work scheme to become, in many respects, unfit for purpose.

The minister for DDP has pledged to carry out a “root and branch” review of the government’s Disability Confident employment scheme, following a decade of criticism from disabled campaigners.

The disability pay gap in Northern Ireland is 18%.

Fair Start Scotland is Scotland’s devolved employment support service, which aims to help people to prepare for and enter sustainable employment. However, only 32% of DDP who joined the programme started work and just 23% stayed in work for 3 months, 19% for 6 months and 14% for 12 months.

## **Engagement, Monitoring and Data**

WeG does not collect or centrally hold data relevant to article 19 rights. In order to research the social care/independent living support situation in England it is necessary to submit Freedom Of Information requests to all 152 LAs.

Although chances for DDPOs to meet with and express views to WeG have increased since 2016, meaningful input into fundamental areas affecting our lives such as those related to the special inquiry are still lacking. The bigger picture is one where DDP are increasingly marginalised and unheard.

WeG frequently refers to engagement with non user-led disability charities.

Department for health and Social Care (DHSC) in particular prioritises engagement with charities and ignores requests to meet with DDPOs.

DDPOs views on new dangerous proposals in the disability and health white paper have not been listened to.

In England, DDP are concerned that the Equality and Human Rights Commission (EHRC) is unable to adequately fulfil its role as a National Human Rights Institution for England and Wales and one that is sufficiently independent from WeG.

Anti-protest legislation forced through by the Home Secretary criminalises peaceful protest and will limit the ability of DDP to get our voices heard and to raise public awareness of issues affecting DDP.

DDP are being disenfranchised by a new voter ID requirement.

At LA level other DDPOs are frightened of speaking out for fear of losing funding and being unable to run user-led services for the benefit of local DDP.

To date in Northern Ireland there is no formal monitoring of the UNCRPD undertaken by Government Departments. The absence of an Executive continues to hinder this work.

To fully implement the recommendations of the 2016 Inquiry, the Scottish Government first needs to identify the best way to measure the cumulative impact of laws, policies and practices including through experiential research, and the data gaps that exist and how to address them.

Intersectional discrimination is a major issue and its impact is not always immediately apparent to policy and decision-makers.

We are concerned about the lack of data on DDP living in Wales. We are particularly concerned about the lack of data on DDP with multiple marginalized identities.

## Housing

DDP are further segregated from society by a lack of suitable housing. There is significant unmet housing need.

WeG policy does not adequately address the lack of suitable housing.

The Equality Act 2010 does not provide sufficient safeguards against housing discrimination.

Problems with housing are compounded by LA and Housing Association failures to carry out repairs and maintenance.

Six years ago, 72 people were killed by a fire that broke out in the Grenfell tower in London. Among them were disabled residents, who due to the chronic shortage of accessible housing, had been housed by their local LA on upper floors with no way to escape in case of fire.

Today DDP are still fighting for protections from fire risks if placed in high-rise housing.

Northern Ireland is experiencing a housing emergency- which is having a severe impact on DDP. DDP are trapped in unsafe and undignified housing.

With respect to housing, it has been proposed that the NI Housing Executive Budget will be reduced. There is a significant deficit in the provision of accessible social homes. The reduction in building will further reduce opportunities for DDP to access an accessible home.

In Scotland, in 2019, 14% of households with a disabled member said their house was not fully accessible. For people living in local authority housing, this was a quarter.

Due to a lack of appropriate accommodation locally in Wales, some DDP have reported having to move far from support networks or feeling forced into certain living situations due to the availability of accommodation.

## Independent living

There is severe and deliberate retrogression of DDP's right to inclusive education in line with WeG's continuing reservation and interpretative declaration on this article.

Placements in segregated "special schools" compared to mainstream education have increased steadily since 1999.

WeG has invested in 59 new free special schools for children with complex SEND and a further 75 are in the pipeline.

Disabled pupils are between 2.5 and 5 times more likely to receive permanent exclusions than non-disabled pupils.

Students who are Deaf/disabled face entrenched barriers to higher education.

WeG continues to employ legislation entrenched in a medical not a human rights approach, which authorises deprivations of liberty based on mental health and learning disability diagnoses.

Following a review of the Mental Health Act 1983, WeG issued a draft Mental Health Bill (2022) as a basis for change. However, the planned changes remain non-compliant with the CRDP.

Pre-pandemic both child and adult mental health services were over-stretched and facing escalating demand set against funding cuts.

A cuts environment combined with the welfare reform agenda has seen provision targeted at those thought to require lower-level interventions.

Between 2015 and 2020 there were 56 mental health-related deaths in England and Wales where coroners identified a lack of staffing or service provision as a "matter of concern".

Support for DDP living in the community has decreased further since 2016 through year-on-year cuts and annual savings targets within adults social care budgets.

For the five years from 2010, the loss of social care funding caused 23,662 additional deaths.

This situation not only reflects further regression under article 19 but has now led directly to significant breaches of many other articles linked to independent living including rights to freedom from torture or cruel, inhuman or degrading treatment or punishment; freedom from exploitation, violence and abuse, personal mobility and respect for the family among others.

DDP are being institutionalised in their homes through grossly inadequate support.

Without adequate support, many DDP are unable to participate in multiple areas of life covered by the CRDP while being at greater risk of crime, exploitation and abuse.

Cuckooing – where criminals take over someone’s home, usually that of a disabled person – is now central within criminal drug operations.

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Children removed from their parents by the State is at the highest level on record.

Community support systems are now so fragile that COVID-19 lockdowns tipped families over the edge. The deaths by neglect of two disabled young women, one in England, the other in Wales, confined in conditions unfit for animals, in separate horrific incidents led to prison sentences for their parents. Local agency failings have been blamed with no accountability from WeG.

Without appropriate community-based support, governments have struggled to de-institutionalise services for people with learning difficulties and autism.

Institutional support places DDP at risk of abuse and neglect within closed cultures.

Government funding for local authorities was cut by 55% between 2010/11 and 2019/20.

As at the end of April 2022, there were 542,000 people waiting for social care support assessments, care packages, direct payments or reviews with social care waiting lists having grown by 37% in less than six months.

The percentage of cases upheld by the Local Government and Social Care Ombudsman (LGSCO) has shown a relentless rise over the last decade.

The faults the Ombudsman finds in its investigations are often not due to one-off staff errors, but are increasingly caused by the measures employed by councils and care providers to mitigate the squeeze on their resources.

The sustainability of the social care support system is in question. One in two councils has had to respond to a care home closure or bankruptcy over the past six months.

Support for DDP to manage Direct Payments and directly employ PAs has been cut to the bone.

Social care charging is having an increasingly detrimental impact on the incomes of DDP, forcing many to go without support while others are trapped in debt.

Social care charges have risen considerably over recent years.

People who are too disabled to work are hit harder by the cost of social care support than those in paid employment since the financial assessment for charging does not take into account earned income.

To date within NI there has been no statutory definition of Independent Living or a coherent strategy through which to promote Independent Living.

NI is experiencing a mental health crisis.

NI has a higher prevalence of mental ill health and a lower per capita spend on mental health than England.

The crisis in social care funding and provision continues to have an adverse impact on DDP's right to independent living in NI.

The Department of Health in NI has withdrawn funding from 62 organisations at the forefront of prevention and early intervention.

During the winter months patients were advised to discharge to care homes due to a shortage of care packages for DDP living in the community.

These actions and also the closure of the Independent Living Fund (ILF) have re-institutionalised DDP.

The demand for social care is increasing and access to funding is decreasing.

The cancellation of the 'Healthy Happy Minds' primary schools counselling programme is a cut to mental health provision for children.

The reduction of expenditure on community aids and adaptations for DDP living in their own home and restrictions on domiciliary care packages will disproportionately impact DDP.

The National Care Service (Scotland) Bill was introduced into the Scottish Parliament on 20 June 2022.

Push back against the Bill from various groups and disagreement means it is unlikely to have the weight it needs to change the system.

Budget cuts are devastating social care support. £22 million of cuts were made to the social care budget in Glasgow City Council alone.

The Scottish Government's commitment to scrap social care charges has not happened.

In Glasgow, the Council can now take up to 75% of a person's available income after housing costs for social care charges. This is especially untenable during a cost of living crisis

Social Care delivery in Scotland faces a number of crises including inadequate resourcing, high levels of vacancies, and geographical variations in care costs.

There is no recognition of this by the Scottish Government.

Budget cuts and staff shortages are driving a culture which lacks empathy and fails to value lived experience and rights to full and equal participation in society.

DDPOs in Scotland have countless examples of DDP trapped in their homes and generally prevented from living a life of their choosing.

Increased demand and limited budgets have put pressure on local authorities' ability to provide access to adequate Self Directed Support (SDS)

Although the Scottish Mental Health Law Review recommended a change in the language used in the Mental Health (Care and Treatment) (Scotland) Act (2003), it also recommended retaining the ability to detain people labelled with learning difficulties in hospital on the grounds of a learning difficulty alone.

Disability Wales has welcomed the Welsh Government's commitment to a National Care Service; however, we do not currently know what the proposed service would look like.

## **Institutionalisation and abuse**

In January 2023, the BBC revealed widespread torture and abuse across several children's care homes in Doncaster. More than 100 reports of appalling abuse and neglect – dating from 2018 to 2021 – were uncovered.

Disabled children and young people are subjected to barbaric treatment in institutional settings which deny their human rights in many areas.

Abuse scandals within segregated settings for children and young people appear in the media but much more goes on that is not exposed with use of physical restraint and seclusion rooms common practice.

Commentators have pointed to substantial profits made by companies delivering services where children are harmed.

Abuse scandals at a number of adult institutions have resulted in large-scale criminal proceedings.

In Essex psychiatric services, around 2,000 people died between 2000 and 2020 while on a mental health ward, or within three months of being discharged.

The lack of appropriate independent living support provision for DDP in NI places them at increased risk of abuse and exploitation including the inappropriate use of restraint and seclusion.

The potential for abuse is greater within institutional settings as demonstrated by the launch of a Public Investigation into events at Muckamore Abbey Hospital and the Older Person's Commissioner's report on Dunmurry Manor both of which include evidence of violence against and the abuse of DDP.

DDPOs in Scotland have countless examples of DDP trapped in their homes and generally prevented from living a life of their choosing.

Many people with a learning disability still do not have choice and control over where they live and who they live with.

The Scottish Government's commitment to reducing the number of people with learning disabilities and complex care needs living in hospitals is too vague and will not be achieved by March 2024.

## 5. Disability Narratives

WeG has not fulfilled the Committee's recommendation to combat negative stereotypes of benefit claimants.

WeG has never acted to challenge false public perceptions of high levels of benefit fraud.

Reports of disability hate crime have risen both on and off line while prosecutions have remained low.

DDP report being affected by a narrative that emerged during the pandemic that their lives are expendable.

The cost of living crisis has also seen a deterioration in attitudes towards DDP in receipt of benefits, reminiscent of those seen when the Committee conducted its Inquiry in 2016.

Since March 2023, political rhetoric has fired up against benefit fraud in an aggressive way.

Media outlets are now attacking claimant of disability benefits, encouraging tax payers to see us as a burden.

Millions more are lost to public finance by DWP error than from benefit fraud.

UK Hate crime law is still not equal for disability.

There is also a lack of legislation for dealing with intersectional discrimination.

## 6. Barriers to justice

Legal challenges have to be brought by individuals who are personally affected within three months. This creates a barrier to redress for discrimination and protection of the rights of DDP.

Tightened financial eligibility rules for legal aid funding in England and Wales have contributed to the barriers to bringing judicial reviews.

Millions of people in England and Wales now live in areas where they can no longer access the help and advice that Parliament has said they are entitled to.

In 2018, the EHRC found: “access to justice has deteriorated” in England and Wales.

WeG’s long-awaited Legal Aid, Sentencing and Punishment of Offenders Act 2012 (LASPO) review and associated Action Plan were disappointing in offering no immediate improvement.

Ten years after the introduction of LASPO, justice is increasingly out of reach for those in most need, as evidenced by new maps from the Law Society of England and Wales showing expanding legal aid deserts.

LA complaints procedures are difficult to navigate. There remains no appeals process under the Care Act.

The availability of community care lawyers to challenge LA decisions over cuts to social care support has drastically reduced due to legal aid cuts. Two thirds of social care users do not have access to professional legal advice.

## **7. Engagement**

On reserved issues, WeG sets UK-wide legislation and policies. Its engagement with DDPOs on these issues should also be UK-wide but this does not happen.

WeG has a tendency to dismiss any criticism of its policies.

## **8. Non-social/human rights model**

WeG's work and social security policies continue to be underpinned not by a social/human rights model approach but by a biopsychosocial one.

This is evident by changes in DWP language: they no longer talk about DDP on income replacement benefits but instead about "claimants on a health journey"; ESA is being replaced by a UC "health" element.

DWP is redefining disability where disability is not according to the Equality Act definition but whether a person has been found to have limited capability for work through one of their notorious functional assessments.

## **9. Monitoring, statistics and data gaps**

There has been a reduction in disability data collection by WeG preventing scrutiny.

The depth and robustness of the evidence that triggered the Special Inquiry can no longer be replicated due to missing information.

We are seriously worried about the lack of UC disaggregated sanctions data which WeG chooses to publish.

DWP has tried to block publication of a number of reports relevant to the impact of its policies on DDP.

WeG social security policies and general approaches continue to lack scientific evidence base.

Underpinning social security policy appears to be a disbelief that the overwhelming majority of those claiming disability benefits are genuinely disabled and face material barriers to paid employment.

Many different factors including WeG's own legislative and policy measures since 2010 are contributing to increasing disability prevalence.

There are no plans to understand this rise as far as we are aware.

## **10. CRDP Importance**

The CRDP has great importance to UK DDP. It is a benchmark against which to defend our rights and a vision of hope for the future.

We are aware how governments share information. Policy trialled on DDP in the UK influences policies then inflicted on DDP in other areas of the world and vice versa.

The special inquiry is important in highlighting the human cost of measures introduced here.

DDP across the UK are lobbying for the CRDP to be enshrined in domestic legislation.

# Alternative Report

# 1. Introduction

1.1 This report provides information on the implementation of Articles 19, 27 and 28 by the UK Government (UKG) since publication in November 2016 of the findings and recommendations from the Committee’s inquiry under article 6 of the Optional Protocol to the Convention on the Rights of Disabled People.

## 1.2 Deaf and Disabled People’s Organisations (DDPOs)

1.2.1 This report has been compiled by Deaf and Disabled People’s Organisations (DDPOs) in England, Wales, Scotland and Northern Ireland (Ni).

1.2.2 DDPOs are organisations run and controlled by Deaf and Disabled people (DDP).

1.2.3 An organisation is a DDPO if: their Management Committee or Board has at least 75% representation of Deaf and Disabled people (DDP); at least 50% of their paid staff team are DDP with representation at all levels of the organisation; they provide services for, or work on behalf of, DDP people; and they follow the social model of disability and an equality and human rights approach in their work.

1.2.4 The organisations and networks who have contributed to this report co-ordinate under the umbrella of the UK DDPO CRDP Monitoring Coalition.<sup>1</sup>

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<sup>1</sup> The following DDPOs have contributed to and support this report: All Wales People First, Alliance for Inclusive Education, Black Triangle, Disability Action (Northern Ireland), Disabled People Against Cuts, Disability Rights UK, Disability Wales, DPO Forum England, Inclusion London, Inclusion Scotland, Liberation, Reclaiming Our Futures Alliance, Scottish DPOs and from Northern Ireland, 1849 individuals and 335 member organisations.

1.2.5 In 2021 we were funded to shadow report ahead of the UK CRDP examination expected to take place in 2022. We consulted extensively with DDP across the UK. That evidence has informed this report. New issues have also arisen since then.

### **1.3 Social Model of Disability**

1.3.1 DDPOs follow the social model of disability and the cultural model of Deafness. These are consistent with a human rights model.

1.3.2 We use the term “Disabled people” rather than “people with disabilities” to emphasise that we are disabled by society and a socially created layer of oppression that we experience on top of our impairments/illnesses/non-normative bodies and/or minds.

1.3.3 According to the cultural model of Deafness, Deaf sign language users identify as a linguistic minority.

### **1.4 Devolution**

1.4.1 Readers are reminded of the devolution framework in the UK.

1.4.2 Where an issue is a “reserved” one, legislation and policy set by the Westminster Government (WeG) can apply to all 4 nations in the UK or to Great Britain (England, Scotland and Wales) or to England and Wales.

1.4.3 Where an issue is “devolved” it is the responsibility of the national governments in Northern Ireland (Ni), Scotland (SG) and Wales (WG). WeG also functions as the national government of England.

1.4.4 The scope of the special inquiry covers issues that are both reserved and devolved.

1.4.5 Some measures the devolved governments have introduced either to mitigate against the harmful impacts of legislation and policy set by WeG

on reserved issues, or to take progressive action in the absence of any from WeG. DDP in England do not have these protections.

- 1.4.6 Responsibility for social care support in England is devolved by WeG to local authorities (LAs) and the devolved nations.
- 1.4.7 Devolution is complex. The range of measures within the scope of the special inquiry are also complex. DDP in the UK need to navigate numerous different systems administered by different bodies all with different eligibility criteria in order to apply for, receive and continue to receive support to which we are entitled.
- 1.4.8 Attempting to compile a UK-wide report on this basis is no straightforward task.
- 1.4.9 The majority of the information contained within the body of this report relates to WeG.
- 1.4.10 Information on measures implemented by WeG in its function as the national government of England or by the governments of the devolved nations is given in Section 4.

## **1.5 Northern Ireland**

- 1.5.1 Northern Ireland is facing a significant political and economic crisis in which severe budget cuts are negatively impacting on disabled people. Services and human rights are being eroded on a daily basis.
- 1.5.2 Decisions to cut funding are being taken by senior civil servants with no accountability. The removal and deep cuts to services will have a disproportionate cumulative impact on DDP which is a breach of section 75 duties.<sup>2</sup>

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<sup>2</sup> [Northern Ireland Act 1998 c. 47, Part VII, Equality of opportunity, Section 75](https://www.legislation.gov.uk/ukpga/1998/47/section/75)  
<https://www.legislation.gov.uk/ukpga/1998/47/section/75>

- 1.5.3 The Northern Ireland Assembly has experienced considerable instability. The collapse of the institutions in 2016 led to a legislative hiatus which further complicated the challenges within the region associated with the legacy of the conflict. NI is experiencing a public funding crisis. The institutions were in operation in early 2020 but collapsed in February 2022.
- 1.5.4 The budget allocated to NI by WeG does not meet requirements.<sup>3</sup>
- 1.5.5 The current equality framework in NI is deeply inadequate. The Equality Act 2010 is also still not applicable in NI despite the previous recommendation of the Committee.
- 1.5.6 We would argue that there are ongoing violations of DDP's rights due to welfare reform, austerity and now also the political crisis in NI. There are around 410,000 DDP in NI.

## **1.6 Intersectionality**

- 1.6.1 DDP experience extra barriers if we have additional protected characteristics and are subject to multiple forms of oppression.
- 1.6.2 Intersectionality is routinely overlooked in policy planning which heightens the levels of risk that DDP are exposed to. This was a serious omission in WeG's National Disability Strategy (NDS).
- 1.6.3 The National Disability Strategy was initially ruled unlawful by the High Court in January 2022 due to a failure to adequately consult with DDP. This judgment was overturned in the Court of Appeal in July 2023.

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<sup>3</sup> [itvNEWS \(2023\). Education, Health and Business representatives react to 2023/24 budget set by secretary of state. \*itv.com\*, 27 April.](https://www.itv.com/news/2023/04/27/education-health-and-business-representatives-react-to-2023-24-budget-set-by-secretary-of-state)

- 1.6.4 The UK has now finally ratified the Istanbul Convention<sup>4</sup> which provides a legal framework to tackle numerous forms of Violence Against Women and Girls (VAWG), including domestic violence, rape, sexual assault, female genital mutilation (FGM), so-called ‘honour-based’ violence, and forced marriage.
- 1.6.5 However, it has two key reservations – in particular, it has not agreed to the provision in Article 59 of the treaty that victim-survivors with insecure immigration status be supported.<sup>5</sup>
- 1.6.6 Deaf and disabled women experience disproportionate levels of domestic violence and face barriers to accessing appropriate support.<sup>6</sup> Women’s Aid Northern Ireland report that 41% of women in refuges and 41% of women accessing outreach services are DDP.<sup>7</sup> Figures are similar across the UK.

## 2. Over-view since 2016

### 2.1 Failure to implement the Committee’s Recommendations

- 2.1.1 UK DDP/DDPOs are overwhelmingly of the view that the Committee’s recommendations have not been implemented.

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<sup>4</sup> [The Conversation \(2022\). What the UK ratifying the Istanbul convention on gendered violence means for women and girls. \*Theconversation.com\*, \[online\] 26 October](#)

<sup>5</sup> Ibid.

<sup>6</sup> [Department for Communities \[DfC\] \(2020\). \*Disability Strategy and Expert Advisory Panel: Report and Recommendations\*. \[online\] pp.59-60](#)

<sup>7</sup> [Women’s Aid Federation NI \(2020\). \*Annual Report 2019-2020\*. \[online\]](#)

- 2.1.2 WeG continues not to monitor article 19 rights. It delegates away responsibility for meeting these with no system for accountability. In England, the situation has deteriorated dramatically further since 2016.
- 2.1.3 Barriers to good work for DDP have increased since 2016 (article 27). This disproportionately impacts on Deaf and disabled workers. WeG's priority is to get DDP out of the social security system whether they have a living income or not.
- 2.1.4 WeG's new social security proposals (article 28), and the accompanying political and media rhetoric are in direct contravention of the special inquiry recommendations.<sup>8</sup>

## 2.2 **Continued and Significant Retrogression**

- 2.2.1 Evidence of further retrogression is particularly stark in relation to those areas covered by the special inquiry – namely independent living and being included in the community, work and employment and adequate standard of living and social protection.
- 2.2.2 There is overwhelming support among DDP for the idea that things have got and are still getting worse for us. 89% of respondents to a survey we conducted to inform our 2022 shadow report were of the opinion that things have got worse since 2017 and 91% that things are still getting worse. Only 2% and 1% disagreed respectively.<sup>9</sup>

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<sup>8</sup> See later section on Disability Narratives regarding rhetoric, p.125.

<sup>9</sup> [Inclusion London \(2022\). Westminster Government Shadow Report: Annex D Survey Analysis. \[online\]](#)

## 2.3 Support to live in the community (article 19)

- 2.3.1 Support to live in the community is devolved. However, this is within the context of austerity and welfare reform enforced by WeG across the UK since 2010.<sup>10</sup>
- 2.3.2 There are significant barriers to and retrogression of rights to independent living across the UK affecting around 1.2 million DDP who use social care support services.
- 2.3.3 The situation regarding support available for DDP to live in the community varies between the different nations.
- 2.3.4 A cumulative impact analysis on living standards of public spending changes commissioned by the EHRC found that:

“In England, households with “more disabilities (measured by the number of functional disabilities recorded across all household members) suffer much larger losses (over £2,900 per year) than those with fewer disabilities, largely because of social care cuts. In Wales, the ‘disability gradient’ is much shallower, while in Scotland households with more disabilities fare slightly better than non-disabled households, due to increased spending on social care, health and social housing.”<sup>11</sup>

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<sup>10</sup> Pearson, C., Brunner, R., Porter, T. and Watson, N. (2020): [Personalisation and the Promise of Independent Living: Where Now for Cash, Care and Control for Disability Organisations Across the UK?](#) *Scandinavian Journal of Disability Research*, 22(1), pp.285–295.

<sup>11</sup> [Reed, H. and Portes, J. \(2018\). The cumulative impact on living standards of public spending changes. Research Report No.120, Manchester: Equality and Human Rights Commission, p.10](#)

2.3.5 The conclusion of the analysis is that:

“The different pattern of distributional impacts of spending cuts seen in Wales and Scotland, compared with England, shows that neither the overall scale of spending cuts in England, nor their precise impact on protected groups, was inevitable.”<sup>12</sup>

2.3.6 WeG closed the Independent Living Fund (ILF) from the end of June 2015. The ILF sat under the Department for Work and Pensions (DWP). It provided cash transfers to severely disabled people to pay for support to enable them to live in the community when the alternative was residential care. At the time of closure there were 18,000 recipients across the UK.

2.3.7 Recipients took two legal challenges against closure – winning the first on appeal and losing the second. The High Court judge noted that “the Minister was sufficiently aware of the very real adverse consequences which closing the fund would have on the lives of many of the more disabled.”<sup>13</sup>

2.3.8 On this basis, they won the second case, having proved the Minister had discharged his equality duty in assessing impact, and closure went ahead.<sup>14</sup>

2.3.9 Austerity has led to the collapse of health and social care in NI.<sup>15</sup> This has been further compounded by the ongoing political and financial crisis in

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<sup>12</sup> Ibid, p.14

<sup>13</sup> Quotation taken from the judgment by Justice Andrews DBE which can be found at: [Aspinall, Pepper & Ors, R \(on the application of\) v Secretary of State for Work and Pensions & Anor \[2014\] EWHC 4134 \(Admin\) \(08 December 2014\)](#)

<sup>14</sup> See later section on mitigating measures, p. 42

<sup>15</sup> <https://scopeni.nicva.org/article/austerity-is-a-choice-and-it-looks-like-a-bad-one>

NI. Reductions in access to domiciliary care, PIP, and the cessation of the ILF have forced disabled people into institutions.

2.3.10 Mental health legislation continues to authorise substitute decision-making, detention in psychiatric institutions, involuntary treatment and the use of community treatment orders.

2.3.11 WeG continues to have in place its reservation and interpretative declaration on CRDP article 24 and in investing in building new special schools.

2.3.12 See Section 4 for key article 19 issues broken down government by government in respect of the devolution framework.

## 2.4 **Barriers to employment (article 27)**

2.4.1 The number of DDP in employment has increased since 2016. WeG met its target to get one million more DDP in work early.<sup>16</sup>

2.4.2 This is not evidence of progress under article 27 and is “meaningless” when it comes to the inequality faced by DDP in the jobs market.<sup>17</sup> Overall employment has increased as have numbers of workers identifying as disabled.

2.4.3 Since 2017, the proportion of the working-age population reporting to the Office for National Statistics (ONS) that they are disabled has risen from 17 per cent to 22 per cent in just five years.<sup>18</sup> Calculations by Professor Vicki Wass from Cardiff Business School calculations show that, once account is taken of the increasing disability prevalence rate, there

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<sup>16</sup> [DWP \(2023\). \*Transforming Support: The Health and Disability White Paper\*. \[online\] CP 807](#), p.9

<sup>17</sup> [Pring, J. \(2022\). Government’s ‘milestone’ disability jobs stats ‘are meaningless when it comes to equality’. \*Disability News Service\*, \[online\] 19 May.](#)

<sup>18</sup> Ibid.

has been no improvement in the disadvantage faced by DDP in the employment market since 2013.<sup>19</sup>

2.4.4 In 2017, the government dropped the more ambitious target to halve the disability employment gap.

2.4.5 Both the National Audit Office (NAO) and the Work and Pensions Committee (WPSC) – in both 2017 and 2021 – raised concerns about the one million target that replaced the pledge to halve the disability employment gap. They recommended that ministers should set a target showing disabled people’s employment compared with the employment of non-disabled people.<sup>20</sup>

2.4.6 Between January to March 2014 and January to March 2023, the UK disability employment gap reduced by 4.8 percentage points (ppt).<sup>21</sup> In the 12 months to January to March 2023, the gap increased by 0.8 ppt, and it is 0.2 ppt higher than before the pandemic in October to December 2019. It currently stands at 29 ppt.

2.4.7 In 2020 the disability employment rate gap in Northern Ireland was 42.2 percentage points, compared to 27.9 ppts for the whole of the UK. Since 2014, the disability employment gap has consistently been higher in Northern Ireland than the rest of the UK.<sup>22</sup>

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<sup>19</sup> Ibid.

<sup>20</sup> Ibid.

<sup>21</sup> [Powell, A. \(2023\). \*Disabled people in employment\*. Research Briefing Number 7540, \[online\] 19 June.](#)

<sup>22</sup> <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-disability-within-northern-ireland-labour-market-2022.pdf>, para 5.1 page 29

- 2.4.8 Disability employment gaps are also above average in the North East of England (34.8 ppt), Scotland (31.6 ppt) and Wales (31.4).<sup>23</sup>
- 2.4.9 The number of “economically inactive” DDP has risen according to latest figures while numbers of unemployed DDP remained the same.
- 2.4.10 There were 4.09 million disabled people of working age in January to March 2023 who were economically inactive. This was an increase of 273,000 from a year before.<sup>24</sup>
- 2.4.11 The inactivity rate for disabled people increased slightly. It was 42.7%, up from 42.5% a year previously. The inactivity rate for people who are not disabled was 14.3%.<sup>25</sup>
- 2.4.12 Difficulties accessing WeG’s Access to Work disability employment support programme have not eased.
- 2.4.13 A backlog of 20,909 AtW cases awaiting decisions on applications were reported in 2022. By 22 March 2022, there were 20,909 DDP awaiting a decision, compared with just 4,890 a year earlier. This was more than twice as high as at the start of the pandemic, in February 2020, when there were about 8,500 DDP waiting.<sup>26</sup>

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<sup>23</sup> [TUC \(2020\). Disability pay and employment gaps. \[online\].](#) Cited in: [TUC \(2021\). Sexual harassment of disabled women in the workplace. \[online\] 19 July](#), p.2

<sup>24</sup> [Powell, A. \(2023\). Disabled people in employment. Research Briefing Number 7540, \[online\] 19 June.](#)

<sup>25</sup> Ibid.

<sup>26</sup> [Pring, J. \(2022\). Access to Work in crisis as figures show ‘massive’ waiting-list. Disability News Service, \[online\] 12 May.](#)

- 2.4.14 In January 2023 it was reported that lengthy delays, often as long as half a year, for applications and claims were putting thousands of DDP jobs at risk.<sup>27</sup>
- 2.4.15 It is estimated the number of Scots currently affected is at nearly 1,800 with hundreds of DDP's jobs and careers put at risk as the numbers waiting for decisions on support has risen over five-fold in just under two years.<sup>28</sup>
- 2.4.16 In addition, disabled people who are recruited to time-limited training and internship opportunities find themselves unable to participate and benefit from such schemes as the reasonable adjustments they need do not materialise in time.
- 2.4.17 Other examples of increasing barriers to employment include increasing disability discrimination within the workplace, intensification of labour and the rise of "bad" work with increasing job insecurity and jobs without protections such as statutory sick pay.
- 2.4.18 Anecdotally we have heard about increasing bullying and harassment in the workplace with managers and colleagues accusing disabled workers with invisible impairments of faking their need for reasonable adjustments.<sup>29</sup>
- 2.4.19 We have also heard about how poverty acts to move DDP further from employment. As society is increasingly digitalised, those who cannot afford digital technology or internet access are increasingly excluded. Photo ID is expensive and without this it is difficult to open a bank

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<sup>27</sup> [RNIB \(2023\). \*Access to Work: People with sight loss cannot wait any longer for action.\* \[online\].](#)

<sup>28</sup> [Williams, M. \(2023\). \*Hundreds of disabled Scots face losing jobs in grants crisis.\* The Herald, 26 January.](#)

<sup>29</sup> See personal testimonies in Annex C

account. In England, public libraries have closed, thus removing opportunities to access the internet for free.

- 2.4.20 Higher numbers of DDP in work is no guarantee they are in suitable work or work that provides a living income.
- 2.4.21 DDP are over-represented among those on low pay.<sup>30</sup> According to the Resolution Foundation, income gaps between DDP and non-disabled people are only partly explained by lower employment rates among DDP. Even after accounting for employment status, more than half of the original income gap remains, showing that in-work DDP face an increased risk of being on lower incomes than their peers.
- 2.4.22 The disability pay gap has widened.<sup>31</sup> Analysis by the Trades Union Congress (TUC) published in October 2020 showed that disabled workers now earned a fifth (20%) less than non-disabled workers, with the disability pay gap widening to £3,800 per year – an increase of £800 since 2019 for someone working a 35 hour week.
- 2.4.23 Seven in 10 (69%) disabled workers earn less than £15ph compared to half of non-disabled workers (50%).<sup>32</sup> Disabled women and disabled workers in the North of England and Wales are more likely to earn less.
- 2.4.24 DDP are over-represented among workers on zero hours contracts.<sup>33</sup> TUC analysis from 2020 found that while 3.1 per cent of non-disabled workers are employed on a ZHC, this rises to 3.8 per cent of disabled workers.

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<sup>30</sup> [El Dessouky, O. and McCurdy, C. \(2023\). \*Costly differences: Living standards for working-age people with disabilities\*. Resolution Foundation BRIEFING, \[online\] January, p.9.](#)

<sup>31</sup> [TUC \(2020\). \*Disabled workers earning a fifth less than non-disabled peers – TUC analysis reveals\*. \[press release\] October 2020.](#)

<sup>32</sup> [TUC \(2023\). \*TUC: 7 in 10 disabled workers earn less than £15 an hour\*. \[press release\] 11 July.](#)

<sup>33</sup> [TUC \(2020\). \*Disability pay and employment gaps\*. \[online\].](#)

- 2.4.25 Intersectional discrimination with regards to disability employment and pay gaps affects workers who belong also to other protected characteristics.<sup>34</sup>
- 2.4.26 According to TUC analysis from 2020, disabled women experience an employment gap of 32.5 per cent compared to non-disabled women and a pay gap of 36 per cent compared to non-disabled men, equivalent to £3.68 per hour.<sup>35</sup>
- 2.4.27 There was a 5.1 ppt difference in employment rates between disabled BME people and disabled white people; the gap between disabled BME workers and non-disabled white people is 34.7 ppt, which is higher than the overall disability employment gap (28.4 ppt).<sup>36</sup>
- 2.4.28 Disabled women workers are more likely to experience sexual harassment in the workplace than non-disabled women workers.<sup>37</sup>
- 2.4.29 Research found that 7 out of 10 (68 per cent) respondents have been sexually harassed at work. This compares to 52 per cent of women in general.<sup>38</sup>
- 2.4.30 The research revealed that disabled women experience higher levels of every type of sexually harassing behaviour and that many disabled women workers experience multiple forms of harassment with more than half of respondents (54 per cent) saying they had experienced two

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<sup>34</sup> [TUC \(2020\). \*Disability pay and employment gaps\*. \[online\]](#). Cited in: [TUC \(2021\). \*Sexual harassment of disabled women in the workplace\*. \[online\] 19 July](#), p.2

<sup>35</sup> Ibid.

<sup>36</sup> Ibid.

<sup>37</sup> [TUC \(2021\). \*Sexual harassment of disabled women in the workplace\*. \[online\]](#)

<sup>38</sup> Ibid.

or more types of sexually harassing behaviour, and 45 per cent saying they had experienced three or more.<sup>39</sup>

## 2.5 Social Security (article 28)

### Poverty

- 2.5.1 7.2 million people in households with a disabled member are living in poverty.<sup>40</sup> This accounts for half of all UK poverty.
- 2.5.2 DDP are almost three times as likely to live in material deprivation than the rest of the population (34 per cent vs 13 per cent).<sup>41</sup>
- 2.5.3 One-in-three (33 per cent) adults in the lowest household income decile are disabled, compared to fewer than one-in-ten (9 per cent) of adults in the highest household income decile.<sup>42</sup>
- 2.5.4 Analysis of the cumulative impact of tax and welfare reform since 2010 commissioned by the Equality and Human Rights Commission (EHRC) shows DDP as among the biggest losers.<sup>43</sup> The more disability within a household, the higher the annual cash loss.

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<sup>39</sup> Ibid.

<sup>40</sup> [Social Metrics Commission \[SMC\], \(2021\). MEASURING POVERTY. \[online\]](#)

<sup>41</sup> Ibid.

<sup>42</sup> [El Dessouky, O. and McCurdy, C. \(2023\). Costly differences: Living standards for working-age people with disabilities. Resolution Foundation BRIEFING, \[online\] January.](#)

<sup>43</sup> [Portes, J. and Reed, H. \(2017\). The cumulative impact of tax and welfare reforms. Equality and Human Rights Commission, \[online\].](#)

- 2.5.5 The report analysed the impact within Great Britain of policy changes made between May 2010 and January 2018, which would have been implemented by the financial year 2021–22.<sup>44</sup>
- 2.5.6 For households with at least one disabled adult and a disabled child, average annual cash losses were just over £6,500, representing over 13% of average net income. Average losses for disabled lone parents with at least one disabled child was almost £10,000 per year.<sup>45</sup>
- 2.5.7 Benefits in the UK are comparatively low by international standards with one of the lowest benefit rates relative to earnings.<sup>46</sup> The basic rate of Universal Credit (UC) is worth around a sixth of average weekly pay.
- 2.5.8 The real value of the standard benefit payment is £40 per month lower than it was in 2010.<sup>47</sup>
- 2.5.9 Use of foodbanks and homelessness have both increased amongst DDP.
- 2.5.10 DDP have consistently been over-represented in foodbank use even before the current cost of living crisis. More than six in ten (62%) working-age people referred to food banks in early 2020 were disabled.<sup>48</sup>

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<sup>44</sup> Ibid.

<sup>45</sup> Ibid.

<sup>46</sup> [Klair, A. \(2023\). \*Benefit levels in the UK\*. TUC consultation response, \[online\] May.](#)

<sup>47</sup> Ibid.

<sup>48</sup> [Trussell Trust \(2021\). \*The state of hunger: it's not right that disabled people are being forced to turn to food banks\*. \[online\]](#)

2.5.11 DDP are more likely to become homeless, and find it harder to exit homelessness into housing.<sup>49</sup>

### **Welfare Reform and Work Act 2016**

2.5.12 The effect of this piece of legislation was found by a cross-Parliamentary group to have been ‘devastating’ to the health and wellbeing of people on low incomes, disproportionately affecting children and DDP.<sup>50</sup>

2.5.13 MPs found overwhelming evidence showing how the Act has pushed many low income households into poverty and financial hardship, and how treatment of those people reliant on social security by the DWP often leaves them feeling worthless and even “dehumanised”.

2.5.14 The four year benefit freeze (2016 – 2020) affected 27 million people while sweeping another 400,000 into poverty.<sup>51</sup> It is not true that this did not affect DDP.<sup>52</sup> In 2019 it was reported that nearly half of disabled people hit by the benefits freeze could not afford essential bills.<sup>53</sup>

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<sup>49</sup> [Stone, B. and Wertans, E. \(2023\). \*Homelessness and disability in the UK\*. Centre for Homelessness Impact, \[online\] May.](#)

<sup>50</sup> [Disability Rights UK \(2021\). Welfare benefit reforms “devastating” to health and wellbeing conclude cross party group of MPs. \*disabilityrightsuk.org\*, \[online\] 25 February](#)

<sup>51</sup> [Barnard, H. \(2019\). End the Benefit Freeze to Stop People Being Swept into Poverty. Joseph Rowntree Foundation, \[online\] 9 March.](#)

<sup>52</sup> DDP who receive out of work benefits all get a standard allowance – which was frozen. Those found eligible for Employment and Support Allowance (ESA) receive an additional component which not frozen.

<sup>53</sup> [Disability Rights UK \(2019\). Nearly half of disabled people hit by the benefits freeze can’t afford essential bills. \*disabilityrightsuk.org\*, \[online\] 1 September](#)

- 2.5.15 With effect from 7 November 2016, the benefit cap was lowered to £20,000 for couples and lone parents outside Greater London (£13,400 for single adults with no children) and to £23,000 for couples and lone parents in Greater London (£15,410 for single 108 targeting disabled people adults with no children).
- 2.5.16 WeG expected roughly half of the households who would lose from the benefit cap to contain someone who is disabled.<sup>54</sup>
- 2.5.17 After it was lowered more than 10,000 households that included a disabled adult had their benefits cut in February 2017, about 15 per cent of the total affected.<sup>55</sup>

### **Replacement of DLA**

- 2.5.18 Substantial numbers of DDP have lost income through the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP).
- 2.5.19 Figures published in June 2018 showed that since the roll-out of PIP, 381,640 disabled people who previously received DLA had been turned down for the new benefit upon reassessment.<sup>56</sup>
- 2.5.20 Loss of DLA/PIP has a wider adverse impact for individuals who then lose other benefits to which DLA/PIP acts as a passport. PIP claimants may be entitled to extra money on top of existing benefits, as well as a reduction in council tax or road tax bills and discounts on travel.

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<sup>54</sup> [DWP \(2012\). Benefit Cap: Equality impact assessment. \[online\]](#)

<sup>55</sup> [Pring, J. \(2017\). Lower benefit cap sees income slashed for more than 10,000 disabled people. Disability News Service, \[online\] 11 May.](#)

<sup>56</sup> Calculated on the basis of 1,264,000 PIP applications being re-assessed DLA claims and 72% of DLA reassessment claims being successful. [Work and Pensions \(2018\). Personal Independence Payment: Official Statistics \[online\]](#)

- 2.5.21 DDP’s mobility has been adversely affected by loss of disability benefits through harsher eligibility requirements such as the PIP 20 metre rule.<sup>57 58</sup> As of January 2020, 102,000 Motability customers had lost PIP awards that entitled them to vehicles to facilitate travel and mobility.<sup>59</sup>
- 2.5.22 In December 2017, the High Court ruled that changes to the PIP regulations brought in by the UKG in an attempt to restrict eligibility to people living with psychological distress, were “blatantly discriminatory”.
- 2.5.23 Had it not been for the one disabled person personally affected by the changes willing to take the case, those discriminatory regulations would still be in place. As a result of the ruling, more than 160,000 DDP were entitled to additional support from PIP.
- 2.5.24 Scottish Government (SG) is using its devolved powers to replace PIP with a new co-produced extra costs disability payment.<sup>60</sup>

### **ESA WRAG Cut**

- 2.5.25 WeG reduced benefit payments for DDP in receipt of Employment Support Allowance (ESA) placed in the “Work Related Activity Group” (WRAG) following a Work Capability Assessment (WCA), in spite of

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<sup>57</sup> [For a more detailed explanation see: DPAC and Inclusion London \(2017\). \*Follow Up Submission: Response to UNCRPD Inquiry Report and UK Government Response\*. \[online\], p.49](#)

<sup>58</sup> For figures relating to PIP and Motability losses calculated 2017-2018 see: [UK DDPO UNCRPD Monitoring Coalition \(2018\). \*Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland – Annual Alternative report from civil society\*. \[online\], p.33.](#)

<sup>59</sup> [Disability Rights UK \(2020\). \*Over 100,000 DLA Claimants Lose Motability Vehicles After PIP Reassessment\*. \*disabilityrightsuk.org\*, \[online\]](#)

<sup>60</sup> See later section on Adult Disability Payment, p. 74

widespread opposition from DDPOs, charities, MPs and members of the House of Lords.

- 2.5.26 As of May 2016, there were 429,000 in the WRAG. The biggest impairment group among these were people with “mental and behavioural disorders”.
- 2.5.27 The £30 per week cut – equivalent to nearly one third of the benefit – applied to new ESA and UC claimants from April 2017.
- 2.5.28 For existing claimants their benefit rate stays the same until they come off it. A claimant leaving the benefit and then needing to reapply later – for example having moved into employment that does not work out – comes back on at the new lower rate.
- 2.5.29 Even before the cut, research had shown that 28% of claimants in the WRAG could not afford to eat.<sup>61</sup>
- 2.5.30 WeG pledged to mitigate losses for new claimants impacted by this cut but these were never delivered.<sup>62</sup>

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<sup>61</sup> [Disability Benefits Consortium \[DBC\], \(2015\). \*Almost 70% of disabled people say cuts to ESA will cause their health to suffer and half may return to work later.\* \[press release\] October 2017.](#)

<sup>62</sup> Penny Mordaunt, Minister for Disabled People at the time of the cut told MPs that she was working at “ensuring that someone’s outgoings can be managed”, and at reducing their “non-work-related costs”, such as energy, broadband and phone bills. When DWP was questioned about this a year later, the only progress made was that WRAG claimants would be told by their jobcentre work coaches how to secure the cheapest BT telephone tariff. [Pring, J. \(2017\). \*Exposed: Mordaunt’s ‘false promises’ on WRAG cut mitigation.\* Disability news Service, \[online\] 6 April.](#)

2.5.31 MPs have received evidence of stress and poverty caused by the cut and that it has acted as a disincentive to employment.<sup>63</sup>

### Universal Credit

2.5.32 WeG pushed on with the roll out of UC despite extensive evidence of adverse impacts, hardship caused by its introduction and concerns that household rather than individual claims would trap women in abusive relationships.

2.5.33 A parliamentary committee found that: “The introduction of Universal Credit is causing unacceptable hardship and difficulties for many of the claimants it was designed to help.”<sup>64</sup>

2.5.34 This is an even greater concern for disabled women who are statistically more than twice as likely to experience domestic abuse than non-disabled women. According to the ONS in 2018, 16.8% of disabled women were subjected to domestic abuse compared to 6.3% of non-disabled women.<sup>65 66</sup>

2.5.35 Concerns raised by the UN Extreme Poverty Rapporteur were dismissed.<sup>67</sup>

2.5.36 We are not aware of any equality impact assessment carried out for the decision to design UC as digital by default.

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<sup>63</sup> [Pring, J. \(2018\). MPs raise concerns with McVey over ‘stress and poverty’ caused by WRAG cuts. \*Disability News Service\*, \[online\] 12 July.](#)

<sup>64</sup> [Public Accounts Committee \[PAC\], \(2018\). Universal credit: delivery causing unacceptable hardship. \[press release\] 26 October](#)

<sup>65</sup> [ONS \(2018\). Domestic abuse: findings from the Crime Survey for England and Wales: year ending March 2018. \[online\], 22 November.](#)

<sup>66</sup> See Appendix 2 for a summary of UC, p. 150.

<sup>67</sup> [Alston, P. \(2018\). \*Statement on Visit to the United Kingdom\*. \[online\].](#)

- 2.5.37 WeG does not record or hold data concerning the prevalence of access, communication and support needs among the benefit claimants directly affected and potentially put at serious risk by policies that assume digital inclusion.
- 2.5.38 DWP has ignored calls for automatic enrolment onto UC of existing benefit claimants. DDPOs and charities have warned that thousands are at risk of destitution because they do not have the skills or support to apply for and maintain a UC claim.<sup>68</sup>
- 2.5.39 There is no Severe or Enhanced Disability Premium under UC. A legal challenge taken by two disabled men who had lost £180 per month after being moved to UC won compensation for others similarly affected but there remains no SDP/EDP for new claimants.
- 2.5.40 DWP resisted fully compensating existing SDP/EDP recipients for their losses resulting in a further three high court hearings, all of which WeG lost. The ruling will affect up to 50,000 people and will involve sums of up to £150 million over a six-year period to put right.<sup>69</sup>
- 2.5.41 In 2018, the NAO raised serious concerns about the way “vulnerable” claimants were being dealt with by DWP as it rolled out UC.<sup>70</sup> DWP has tried to block from publication a report commissioned into the effectiveness of support for vulnerable UC claimants.
- 2.5.42 WeG has invested in free support delivered by Citizens Advice to help make UC claims. This is not adequate to prevent DDP falling through the gaps when their legacy benefits stop. It is offered online or by

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<sup>68</sup> [Butler, P. \(2020\). \*Universal credit could 'steamroll vulnerable into poverty'\*. \*The Guardian\*, \[online\] 11 February.](#)

<sup>69</sup> [Leigh Day \(2022\). \*Severely disabled benefits claimants win legal challenge over loss of income caused by move on to Universal Credit\*. \[press release\] 21 January.](#)

<sup>70</sup> [NAO \(2018\). \*Rolling out Universal Credit\*. \[online\], HC: 1123, 2017-19.](#)

telephone. Those unable to access support via these channels, are told to contact their local Jobcentre.

### **Benefit Assessments**

- 2.5.43 Benefits assessments continue to cause widespread distress among DDP, stress on our families/support networks and strain on support services.<sup>71</sup> The issues are the same that we have been reporting for over a decade.
- 2.5.44 Despite five independent reviews of the Work Capability Assessments (WCA) and two for the PIP assessment, too little has changed.
- 2.5.45 Speaking to a Parliamentary Committee, one of the assessment reviewers described “systematic bias” within the operational side of the DWP and that “things just haven’t been taken forwards.”<sup>72</sup> He said “I think it would be useful to have another review, absolutely. If one were to do that I would go back and not just look at the Work Capability Assessment but look more fundamentally at the whole concept of what we are doing.”<sup>73</sup>
- 2.5.46 The scale of impact that these assessments have is considerable. According to the latest available figures, 1.6 million people claim ESA, 1.7 are on UC health and 4.2 million people claim either PIP or DLA.<sup>74</sup>

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<sup>71</sup> See personal testimonies in Annex C: Voices and lived experience, p. 243

<sup>72</sup> [UK Parliament \(2021\). Experts questioned on flaws in assessments for disability and health-related benefits. \[press release\] 30 November.](#)

<sup>73</sup> [WPSC \(2021\). Oral evidence: Health assessments for benefits, HC 604, \[online\] 1 December, Q4.](#)

<sup>74</sup> [DWP \(2023\). DWP benefits statistics: August 2023. \[online\] 15 August](#)

Assessments are not only to apply for the benefit but the vast majority of claimants are called up to reassessment every couple of years.

- 2.5.47 When WPSC held an inquiry into ESA and PIP assessments they received such an unprecedented volume of evidence that alongside the inquiry report and recommendations,<sup>75</sup> they brought out a second publication of claimants' testimonies.<sup>76</sup>
- 2.5.48 Their follow up report published in July 2023 concluded that many of the "significant problems" with the assessments found by their predecessor Committee remain.<sup>77</sup>
- 2.5.49 This is despite some improvements – however important changes to improve trust and transparency have not been made, and the system continues to let down some of the "often vulnerable people" who rely on it.<sup>78</sup>
- 2.5.50 DDP live in constant anxiety about being called up for reassessment. This has a detrimental impact on people's mental health.
- 2.5.51 The assessment process is complex, requiring lengthy form filling, gathering recent medical evidence and attendance at assessment.
- 2.5.52 Not all assessment centres are accessible and can be many miles from a person's home.
- 2.5.53 Lateness counts as a no-show; missing an assessment is punished with benefits stoppage. Claimants have no control over the time or the date of their assessment. Home visits are difficult to obtain.

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<sup>75</sup> [WPSC \(2018a\). PIP and ESA Assessments. HC 829, 2017-2018 \[online\] 14 February](#)

<sup>76</sup> [WPSC \(2018b\). PIP and ESA Assessments: claimant experiences. HC 355 \[2017-2018\], 8 February.](#)

<sup>77</sup> [WPSC \(2023\). Health assessments for Benefits. \[online\] HC 128 p.7](#)

<sup>78</sup> Ibid.

- 2.5.54 During the pandemic face to face assessments were replaced with telephone assessments or decisions made on the basis of the written evidence that was submitted. This was not suitable for all but for many others represented a significant improvement. This has been largely retained post-pandemic.
- 2.5.55 Disabled people are carers too. 62% of carers have some form of illness or impairment.<sup>79</sup> Insufficient attention is paid to this overlap within policy-making, including the cumulative burden on families going through multiple assessments.
- 2.5.56 The assessment process is emotionally draining. It requires the claimant to spend considerable time within a short period (claimants typically have less than a month to complete their re/assessment forms) focusing exclusively on their limitations and what those mean within their day-to-day lives.
- 2.5.57 They also need to collect evidence from others involved in their lives – medical professionals but also family/friends/support workers – regarding what support they require.
- 2.5.58 In 2013 the high court ruled that the WCA discriminates against people living with mental distress by requiring them to collect and send off their own evidence when this might not be something they are able to do.<sup>80</sup> The burden of evidence still lies with the claimant.
- 2.5.59 Interaction with benefit assessors can be highly distressing, for example due to insensitive questions such as asking claimants with mental distress why past suicide attempts have failed, insisting

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<sup>79</sup> [Statista \(2019\). Share of illnesses or disabilities, if any, of carers in England in 2018/19. \[online\], June](#)

<sup>80</sup> [Public Law Project \(2013\). Work Capability Assessment discriminates against claimants with a mental health disability. \[press release\] 22 May](#)

claimants participate in physical examinations that cause them pain and hostile attitudes.

- 2.5.60 DDP frequently describe “lies” written in their assessment reports. This theme was picked up by the WPC inquiry who commented in their report that: “Central to the lack of trust are concerns about the ability of the Department’s contractors to conduct accurate assessments.”<sup>81</sup>
- 2.5.61 DDP have for many years called for audio recordings of assessments to be provided by default (with an opt out option), believing that this would improve the accuracy of assessment reports. We welcome moves towards this but DWP has been slow to implement.<sup>82</sup>
- 2.5.62 The quality of assessment reports has been a constant issue since they were introduced. WPSC found evidence of “systematic poor quality”.
- 2.5.63 Government figures released in May 2018 suggest that tens of thousands of ESA benefit claims could have been decided by civil servants on evidence from assessment reports that should have been rejected because their quality was “unacceptable.”<sup>83</sup>
- 2.5.64 This has a direct impact on DDP through wrongful decisions which find no eligibility for benefits. The rate of assessment decisions over-turned at appeal stood at 75% for both ESA and PIP in quarterly statistics for June – April 2019.<sup>84</sup>
- 2.5.65 Data gaps under UC make it more difficult to understand the current situation. For example, we no longer have information about how

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<sup>81</sup> [WPSC \(2018\). PIP and ESA Assessments. HC 828, 2017-2019 \[online\] 14 February](#), p.3

<sup>82</sup> [DWP \(2021\). Shaping Future Support: The Health and Disability Green Paper. CP 470, \[online\] p.40](#)

<sup>83</sup> [Pring, J. \(2018\) DWP figures on ‘unacceptable’ WCA reports cast doubt on decisions made on tens of thousands of ESA claims \[online\] Disability News Service.](#)

<sup>84</sup> [MoJ, \(2019\). Tribunal Statistics Quarterly, April to June 2019 \(Provisional\). \[online\].](#)

many disabled claimants are being found “Fit for Work”; new benefit applicants go onto UC where published data is not disaggregated by disability.

- 2.5.66 In 2013, WeG introduced an additional stage to the assessment process called “Mandatory Reconsideration” (MR) which claimants must go through before they can appeal against being turned down for benefits/having benefits reduced after re-assessment.
- 2.5.67 There is no set timeframe for MR. The claimant is not eligible to the benefit while going through MR, although if found eligible at appeal would then receive a back payment.
- 2.5.68 The majority of MRs rubber stamp the original decision.<sup>85</sup> Between 2013 and 2018, only 11% of MRs for ESA over-turned the original decision whereas at appeal 60% of decisions were over-turned; for PIP the figure was 19% over-turned at MR and 63% at appeal.
- 2.5.69 The introduction of MR has undoubtedly discouraged claimants to go to appeal. In 2020, the High Court ruled that forcing claimants to go through MR for ESA was unlawful.<sup>86</sup> It remains in place for PIP.
- 2.5.70 Once claimants reach appeal stage and before their case is heard by tribunal, they are eligible for a standard rate of ESA if their doctor sends a note saying the person is unfit for work. In 2018 it emerged that DWP had been writing to doctors instructing them not to issue the notes, thus leaving claimants with no income while waiting for

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<sup>85</sup> [WPSC \(2018\). PIP and ESA Assessments. HC 828, 2017-2019 \[online\] 14 February](#), p.7

<sup>86</sup> [Connor, R \(On the Application Of\) v The Secretary of State for Work And Pensions \[2020\] EWHC 1999 \(Admin\)](#)

For an explanation of what the judgement means and who it applies to, see: [Disability Rights UK \(2020\). High Court rules mandatory reconsideration requirement for ESA claimants unlawful. Disabilityrightsuk.org, \[online\] 11 August.](#)

their appeal to be heard. In January 2019 the Chair of the WPSC wrote to the Minister for Disabled People asking about this.<sup>87</sup>

- 2.5.71 In 2022 a DWP whistleblower warned that harsh new policies were forcing more DDP to attend weekly face-to-face jobcentre meetings under threat of sanction while waiting for the outcome of their WCA and while it was clear that they would be put into the LCWRA group – and therefore be exempt from attending mandatory meetings.<sup>88</sup>
- 2.5.72 Reassessment puts DDP under threat of having all or a substantial part of our income stopped. DDP unable to navigate the complex assessment process and without support are put in situations of high risk.
- 2.5.73 Despite this, WeG does not accept a safeguarding duty for benefit claimants. They have continuously declined to call for an inquiry into benefit-related deaths. According to the previous Secretary of State for Work and Pensions, safeguarding is the responsibility of local agencies such as social services departments and doctors' surgeries.<sup>89</sup>
- 2.5.74 A survey conducted in association with a Channel 4 documentary on benefit deaths found that of 3,500 survey respondents, 13 per cent said they had attempted suicide as a result of interacting with the

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<sup>87</sup> [Field, F. \(2019\). Letter to Sarah Newton, Minister for Disabled People, 11 January.](#)

<sup>88</sup> [Pring, J. \(2022\). DWP is forcing distressed claimants to attend weekly meetings, says whistleblower. Disability News Service, \[online\] 10 March](#)

<sup>89</sup> [WPSC \(2020\). Oral evidence: DWP's response to the coronavirus Outbreak. HC 178, \[online\] 30 September, Q230](#)

<sup>90</sup> [UK Parliament \(2021\). Disabled people's experiences of the benefits system: Work and Pensions Secretary given 'final chance' to publish report. \[press release\] 16 December.](#)

DWP.<sup>91</sup> A third said it had caused them to plan suicide, while 61 per cent said the way the system is implemented led them to have suicidal thoughts.

- 2.5.75 An inquest into the death of Philippa Day in 2021 identified 28 instances where “systemic errors” by both the DWP and the assessment provider contractor had led to failures in the handling of her benefit claim.<sup>92</sup>
- 2.5.76 In December 2021, another coroner wrote to the DWP calling for urgent action after a severely ill benefit claimant died as a result of being told by DWP that he had to leave hospital to attend a benefits appointment in person or his claim would be stopped.<sup>93</sup>
- 2.5.77 Five bereaved families have more recently called for a public inquiry to be held into benefit deaths.<sup>94</sup> Appendix 1 lists benefit deaths that have occurred since 2017.<sup>95</sup>
- 2.5.78 WeG expanded the terminal illness "six month rule" to twelve months in response to the threat of legal action. This is welcome. Figures revealed that more than 100 terminally ill people were being turned down for PIP each month despite having less than six months to live.<sup>96</sup>

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<sup>91</sup> [Smallman, E. \(2021\). The truth about disability benefits: ‘People are killing themselves because of this system’. \*iNews\*, \[online\] 16 December](#)

<sup>92</sup> [Clow, G. \(2021\). \*Regulation 28: REPORT TO PREVENT FUTURE DEATHS Philippa Jane Louise Day \(died 16 October 2019\)\*. \[online\] 12 February. Leigh Day \(2021\). \*Conclusion of inquest into death of Philippa Day\*. \[press release\] 27 January.](#)

<sup>93</sup> [Hayes, S. \(2021\). \*ANNEX A – REGULATION 28: REPORT TO PREVENT FUTURE DEATHS \(1\)\*. \[online\] 3 December](#)

<sup>94</sup> [Express and Star \(2021\). Bereaved families call for public inquiry into deaths of benefits claimants. \*expressandstar.com\*, 20 July](#)

<sup>95</sup> p. 141

<sup>96</sup> [APPG for Terminal Illness \(2019\). \*Six Months To Live?\* \[online\]](#)

- 2.5.79 However, the cost of this concession will be off-set by WeG reneging on its pledge to limit reassessments for those with unchanging or degenerative conditions.<sup>97</sup> Policy costings attached to the 2021 Autumn Budget estimate that the combination of these two measures will make a projected saving of £70 from 2022/3 – 2024/5.
- 2.5.80 The Health and Disability Green Paper mentions the need for an “affordable” benefits system in several places.<sup>98</sup>
- 2.5.81 Nothing has been done to bring benefit assessments in line with a human rights approach and they continue to be underpinned by the Waddell-Aylward biopsychosocial model of disability which is contrary to this.<sup>99 100</sup>

### **Benefit Deaths**

- 2.5.82 Deaths and suicides linked to benefit changes continue to happen.
- 2.5.83 The number of Internal Process Reviews (IPRs) carried out by DWP to investigate allegations of inadequate case handling that may have

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<sup>97</sup> [HM Treasury \(2021\). Autumn Budget and Spending Review 2021: Policy Costings.\[online\] October](#), p.54

<sup>98</sup> DWP (2021). *Shaping Future Support: The Health and Disability Green Paper*, [online] July, CP470, p.37; p.56; p.57; p.61; p.67

<sup>99</sup> For confirmation of the role of the BPS model within welfare reform see comments to Parliament made by Lord Freud. [Hansard HL Debate,17 January 2012, col. 496.](#)

<sup>100</sup> For a good explanation of how the Waddell-Aylward model is contrary to a human rights approach see: [Shakespeare, T., Watson, N., & Alghaib, O. A. \(2017\). Blaming the victim, all over again: Waddell and Aylward’s biopsychosocial \(BPS\) model of disability. Critical Social Policy, vol. 37, no. 1, pp. 22–41](#)

resulted in serious harm more than doubled in the three years from July 2019.<sup>101</sup>

- 2.5.84 WeG has repeatedly rejected calls for an independent inquiry.<sup>102 103</sup>
- 2.5.85 Hundreds of recommendations for improvements have been made by DWP's own secret reviews into the deaths of claimants.<sup>104</sup> Some of these show DWP staff continuing to make the same fatal errors, and the absence of a system to track actions in response to recommendations.
- 2.5.86 There is credible evidence of a culture of hostility towards benefit claimants within DWP.
- 2.5.87 Research undertaken with DWP staff into the huge increase in sanctioning rates between 2010 and 2013 has revealed deliberate use of psychological harm as a technique to reduce the number of people claiming benefits.<sup>105</sup>
- 2.5.88 After spending 18 months at the DWP on secondment from the policy and campaigns department of mental health charity Mind, Tom Pollard concluded that the "DWP is institutionally and culturally incapable of making the reforms needed to achieve such a shift in

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<sup>101</sup> In the absence of this WPSC is now undertaking its own inquiry into safeguarding "vulnerable" claimants. [WPSC \(2023\). Safeguarding vulnerable claimants: Work and Pensions Committee launches new inquiry. \[press release\] 21 January](#)

<sup>102</sup> See government response here: [Petition \(2019\). Justice for Jodey Whiting: Independent inquiry into deaths linked to the DWP. \*petition.parliament.uk\*, \[online\]](#)

<sup>103</sup> [WPSC \(2023\). Safeguarding vulnerable claimants: Work and Pensions Committee launches new inquiry. \[press release\] 21 January](#)

<sup>104</sup> [Pring, J. \(2023\). MPs launch inquiry into DWP safeguarding, after decade of deaths. \*Disability News Service\*, \[online\] 20 July](#)

<sup>105</sup> [Redman, J. and Fletcher, D. \(2021\). Violent bureaucracy: a critical analysis of the British public employment service. \*Critical Social Policy\*, 42 \(2\), pp. 306-326](#)

outcomes for ill and disabled people, or for ‘harder-to-help’ groups more widely”. He authored a report with think tank Demos recommending the DWP be stripped of its responsibilities.<sup>106</sup>

## Sanctions

- 2.5.89 Benefit sanctions are proven to discriminate against DDP and cause considerable avoidable harm.
- 2.5.90 Sanctions are when a benefit claimant has their benefit payments stopped because they have not complied with a condition imposed on them by the benefit regime. Some conditions are part of the system and some are discretionary and applied by a local work coach at a job centre where the claimant is required to attend.
- 2.5.91 Research has shown that disabled job seekers were 26 – 53% more likely to receive a sanction than non-disabled job seekers.<sup>107</sup>
- 2.5.92 Sanctions have been linked to the deaths of disabled claimants and to increased foodbank use. When sanctions were at a high point under the Coalition government 2010 – 2015, sanctions were linked to one in five benefit deaths investigated by DWP.<sup>108</sup>
- 2.5.93 Studies found that increases of 100 sanctions per 100,000 people led to increases of between 2 and 36 food parcels per 100,000 people.<sup>109</sup>

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<sup>106</sup> [Savage, M. \(2019\). Unfit DWP should be axed, says thinktank. \*The Guardian\*, \[online\] 19 January](#)

<sup>107</sup> [Geiger, B.B. \(2018\). \*A Better WCA is Possible\*. London: Demos, p.17.](#)

<sup>108</sup> [Pring, J. \(2015\). One in five benefit-related deaths involved sanctions, admits DWP. \*Disability News Service\*, \[online\] 15 May \[Welfare Conditionality Project \\(2019\\). \\*Final Findings Report\\*. \\[online\\] p.4\]\(#\)](#)

<sup>109</sup> [Stewart, J. \(2021\). Austerity policies linked to increased foodbank use and food insecurity. \*imperial.ac.uk\*, \[online\] 17 March](#)

- 2.5.94 The welfare conditionality project reports that benefit sanctions routinely trigger profoundly negative personal, financial and health impacts that are likely to move people further away from the paid labour market.<sup>110</sup>
- 2.5.95 Hardship payments are available for sanctioned claimants but these are loans deducted from future benefits, reducing further already below poverty level payments.
- 2.5.96 Both sanctions and the experience of conditionality itself are linked to adverse impacts on mental well-being. Research found that conditionality for Deaf and Disabled job-seekers is itself literally “mad-making”.<sup>111</sup>
- 2.5.97 DWP staff have reported pressure from managers to apply sanctions.<sup>112</sup>
- 2.5.98 In March the Chancellor announced an intensification of the conditionality regime.<sup>113</sup>
- 2.5.99 The trade union representing DWP staff has described this as new sanctions regime as a “massive attack” on benefit claimants.<sup>114</sup>
- 2.5.100 We are extremely concerned about the impact of this on DDP.

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<sup>110</sup> [Welfare Conditionality Project \(2019\). Final Findings Report. \[online\] p.4](#)

<sup>111</sup> Mehta, J., Clifford, E., Taggart, D. and Speed, E. (2018). When your mental health disappears overnight: Constant anxiety of benefit sanctions is toxic for mental health of disabled people. *Clinical Psychology Forum*, (312), 4-6

<sup>112</sup> [Cardwell, P. \(2014\). Union claims targets for benefit sanctions do exist in Jobcentres. \*Third Force News\*, 9 May.](#)

<sup>113</sup> [HM Treasury and Hunt, J. \(2023\). Spring Budget 2023 speech. \[online\] 15 March](#)

<sup>114</sup> [Furze, C. \(2023\). New sanctions regime is 'massive attack' on Universal Credit claimants, says DWP staff union. \*ChronicleLive\*, \[online\] 28 March.](#)

2.5.101 A new draft report which DWP tried to block from publication shows that sanctions push DDP out of the social security system onto no recorded income at double the exit rate without sanction.<sup>115</sup>

### Scrapping the WCA

2.5.102 In its new health and disability white paper (*'Transforming Support'*), WeG now proposes to end the WCA.<sup>116</sup> Instead, both out-of-work and extra costs disability benefits will depend upon the one PIP assessment. This is a deeply regressive move.

2.5.103 PIP assessments are not designed to test for work capability. The same problems with the WCA are associated with PIP assessments. 91% of appeals are won by claimants on the same evidence that the DWP held when they were turned down with no new evidence provided and in just a tiny 1% of cases it was new written evidence, for example a medical report, that swung the outcome.<sup>117</sup>

2.5.104 By scrapping the WCA and replacing it with just one assessment, DDP found ineligible will lose both benefits at once.

2.5.105 The WPSC has called on WeG "Prior to any changes to the health assessment process, including the abolition of the WCA" to conduct an external assessment on "the potential physical and mental health

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<sup>115</sup> [DWP \(2023\). \*The Impact of Benefit Sanctions on Employment Outcomes: draft report.\* \[online\], 6 April](#)

<sup>116</sup> [DWP \(2023\). \*Transforming Support: the health and disability white paper.\* \[online\] CP 807 p.34](#)

<sup>117</sup> [Disability Rights UK \(2022\). \*7 in 10 PIP appeals won on the same evidence DWP already held.\* \[disabilityrightsuk.org.uk\]\(https://disabilityrightsuk.org.uk\), \[online\] 4 October](#)

effects of these changes on affected claimants.”<sup>118</sup> However, WeG has already begun to draft the legislation to introduce these changes.

- 2.5.106 Currently 632,000 DDP get out-of-work disability benefits but not PIP.<sup>119</sup> WeG proposes existing claimants in this situation get transitional payments. These will not increase with inflation.<sup>120</sup> New claimants found ineligible for PIP will only have the standard UC allowance to live on. The standard allowance is deliberately set at a rate too low to sustain anyone for more than a short period and is therefore inappropriately low for Deaf and disabled benefit claimants who face barriers to employment.
- 2.5.107 Claimants who get PIP will get a new UC “health element” on top of the new standard out-of-work benefit allowance.<sup>121</sup> There will no longer be a category of benefit that automatically exempts those in it from conditionality and sanctions, described by WeG as introducing “a new personalised health conditionality approach.”<sup>122</sup>
- 2.5.108 Work coaches will decide what level of work-related activity each individual claimant, including those in receipt of the new UC “health element”, is expected to perform in return for their benefits.
- 2.5.109 DDP/DDPOs are concerned that work coaches are not equipped to make these decisions even with more training.

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<sup>118</sup> [WPSC \(2023\). Health assessments for Benefits. \[online\] HC 128](#) p.7

<sup>119</sup> [Pursgrove, T. \(2023\). Social Security Benefits: Disability. UK Parliament: Written answer, 9 March, HC 156196](#)

<sup>120</sup> [DWP \(2023\). Transforming Support: the health and disability white paper. \[online\] CP 807](#)  
p.34

<sup>121</sup> Ibid. p.34

<sup>122</sup> Ibid. p.34.

2.5.110 Under the old system, medical professionals treating claimants gave their recommendations for disability benefit eligibility. Under the system rolled out since 2010, DDP are assessed by generalised medical professionals employed by outsourced providers. Lack of specialised knowledge has been linked to wrongful decisions. Work coaches have no medical qualifications at all and are paid substantially less than medical professionals.

### **In-work Conditionality**

2.5.111 “In-work progression” will be mandatory from September 2023, initially affecting around 600,000 claimants.<sup>123</sup>

2.5.112 In-work progression is where claimants who are in work but also claiming benefits due to low incomes are required to undertake job search activity to look for more or better paid work.

2.5.113 When fully rolled out, it will affect 1.2 million of which 27% are DDP.<sup>124</sup>

2.5.114 Other protected characteristics are also disproportionately impacted, for example 77% are women, 18% come from an ethnic minority and 21% are people who speak English as a second language.<sup>125</sup>

2.5.115 Claimants in work but earning under the “Administrative Earnings Threshold” (AET) are subject to more intensive in-work conditionality which can include up to 35 hours per week job search activity on top of a claimant’s existing job.

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<sup>123</sup> [DWP \(2023\). \*Transforming Support: the health and disability white paper\*. \[online\] CP 807 p.18-19](#)

<sup>124</sup> [DWP \(2021\). \*The Future Cohort Study: understanding Universal Credit’s future in-work claimant group\*. \[online\] 1 July](#)

<sup>125</sup> Ibid.

- 2.5.116 The AET was increased in the 2023 Spring meaning more claimants are now affected, increased from the equivalent of 15 hours to 18 hours at National Living Wage for an individual claimant, meaning that anyone working below this level will be subject to “a more intensive conditionality regime.”
- 2.5.117 DDP are over represented in both low paid and part time work and are disproportionately impacted by these measures.
- 2.5.118 Whilst they may be able to work part-time, they may not be able to engage in work search activity on top of that and either work more hours or find a higher paying job. They also face the same barriers to work related activity as out of work benefit claimants such as digital exclusion.
- 2.5.119 Once they are migrated to UC we will not be able to see if DDP are being discriminated against by this policy as published data on UC is not disaggregated by disability.

## 2.6 Mitigations

- 2.6.1 Various mitigating measures have been adopted by the respective governments to lessen the harmful impacts of the austerity and welfare reform measures implemented by WeG.

### Scotland

- 2.6.2 In 2021, the Independent Review of Adult Social Care recommended that the Independent Living Fund Scotland (ILFS) be reopened to new applicants.

- 2.6.3 DDPOs have been calling for this for many years. A re-opened ILFS would provide welcome and early progress pending the longer-term development of a National Care Service.<sup>126</sup>
- 2.6.4 Despite apparent support from the Scottish Government (SG), no progress has been made.
- 2.6.5 DDP and DDPOs welcomed the commitment from SG and Social Security Scotland (SSS) to human rights and the principles of fairness, dignity and respect. However, there was a failure to include a legal duty to comply with any international standards.<sup>127</sup>
- 2.6.6 There are concerns that human rights rhetoric is not always implemented in practice.
- 2.6.7 For example, it has been reported that SSS has declined to accept applications via letter, despite committing to accept applications in any format accessible to the individual.
- 2.6.8 There are also reports of issues with SSS refusing to deal with DDP's representatives despite mandates being provided for this.
- 2.6.9 Time taken to process Adult Disability Payment (ADP) and Child Disability Payment has increased and processing times vary from a few weeks to over six months in more complex cases.

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<sup>126</sup> See Section 4 for more information on the National Care Service, p. 114

<sup>127</sup> [Scottish Human Rights Commission \(2018\). \*Commission calls for 'due regard duty' to advance right to social security.\* \[press release\] 31 January](#)

- 2.6.10 SSS has said that it is working to speed up processing times.<sup>128</sup>  
However, these delays are causing undue hardship for DDP.<sup>129</sup>
- 2.6.11 SG has prioritised a ‘safe and secure’ transition of benefits including retaining rules from the WeG system such as the 50% rule<sup>130</sup> and 20-metre walking test<sup>131</sup> which are strongly opposed by DDP and do not uphold the human rights model of disability.<sup>132</sup>
- 2.6.12 An Independent review of ADP is due to begin after Summer 2023.
- 2.6.13 The review must be coproduced with DDP, sufficiently resourced and have appropriate terms of reference in order to plan improvements that progress DDP’s human rights to social protections.
- 2.6.14 The Scottish Government continues to take measures to mitigate the impact of the benefit cap, including through increasing funding for discretionary housing payments which support people with housing and living costs.<sup>133</sup>

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<sup>128</sup> Scottish Parliament Information Centre (2023), [Scottish Social Security: Application Processing Times](#)

<sup>129</sup> [‘Significant delays’ to new disability benefits – BBC News](#)  
[Scottish Social Security: Application Processing Times – SPICe Spotlight | Solas air SPICe \(spice-spotlight.scot\)](#)

<https://www.gov.scot/publications/adult-disability-payment-high-level-statistics-to-30-april-2023/>

<sup>130</sup> The 50% rule says that to qualify for the benefit you must be impacted by your condition, to the extent set out in the descriptors (for example be unable to prepare and cook a meal or to get dressed) on at least half the days (50%) in every month.

<sup>131</sup> The 20 metre walking rule states that if you can walk more than 20 metres, aided or unaided, then you do not get the points you need for Enhanced Mobility component.

<sup>132</sup> [Adult Disability Payment \(Mobility Component\) GDA Consultation Response • Glasgow Disability Alliance](#); [Inclusion Scotland ADP Consultation Response](#)

<sup>133</sup> [Helping families with their living costs – gov.scot \(www.gov.scot\)](#)

## Wales

- 2.6.15 *Action on Disability: Framework for Independent Living* is an action plan aimed at reducing or removing social barriers to equality experienced by disabled people.
- 2.6.16 The policy identified these areas of concern “advice and information, advocacy; personal care and support; person centred technology; employment; housing; transport; and access to places.”
- 2.6.17 The Socio-economic Duty, established in 2020, requires all public bodies in Wales to consider the impact on those with socio-economic disadvantage in all their activities.<sup>134</sup>
- 2.6.18 LAs in Wales reported encouraging short-term results from the Duty and have identified supporting those with some protected characteristics, namely DDP and racialised people as key targets.<sup>135</sup>
- 2.6.19 The Social Services and Wellbeing (Wales) Act (2014) was referred to by DDP responding to a Disability Wales survey as not fully delivering on what was promised.
- 2.6.20 The Act was designed alongside DDP/DDPOs and imposes duties on local authorities, health boards, and Welsh Ministers to promote the well-being of disabled people and carers.<sup>136</sup>

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<sup>134</sup> Welsh Government, “Socio-economic duty: an overview”, 14th September 2020, <https://www.gov.wales/socio-economic-duty-overview>

<sup>135</sup> Elaine Wilson Smith, Diego Garcia Rodriguez and June Brawner, Equality and Human Rights Commission, “Evaluating the socio-economic duty in Scotland and Wales”, 2<sup>nd</sup> March 2021, <https://www.equalityhumanrights.com/sites/default/files/evaluating-the-socio-economic-duty-in-scotland-and-wales.docx>

<sup>136</sup> [Welsh Government, \(2014\). \*Social Services and Wellbeing \(Wales\) Act 2014\*](#)

2.6.21 The Act has been in action since 2016, but 6 years on and according to DDP we spoke to, many of the stated issues remain.<sup>137</sup>

### 3. New Issues

#### 3.1 EU withdrawal

3.1.1 EU withdrawal followed by the pandemic has dramatically exacerbated the recruitment crisis in social care.

3.1.2 In spite of being made aware of the problems individual disabled people have in recruiting PAs and being unable to use any sponsorship routes, Migration Advisory Committee (MAC) and WeG have continued to refuse to put any scheme in place that would enable individual PA employers to recruit from abroad more easily since our withdrawal from the EU.

3.1.3 WeG recently announced it is providing £600 million to help with recruitment and retention in social care. It has also been reported that millions spent on social care recruitment campaigns have been largely ineffective.

3.1.4 Almost £6.5 million was budgeted for the adult social care recruitment campaign for 2021/22. A total of £23,650,000 has been budgeted for the campaign since 2018, including a projection for the 2022-23 year.

3.1.5 In adult social care in England as at 2021/22 there were 165,000 vacant posts, up 55,000 or 52% since 2020/1.<sup>138</sup>

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<sup>137</sup> "The 2014 Act should have been a protective measure but most local authorities have ignored or resisted it" – respondent to 2023 Disability Wales survey.

<sup>138</sup> [Skills for Care \(2022\). \*The state of the adult social care sector and workforce in England.\* \[online\] October.](#)

- 3.1.6 Disabled people living in their own homes now face even greater barriers to recruiting Personal Assistants (PAs). This was an issue on which we received numerous submissions in our consultation for the 2022 shadow report.
- 3.1.7 The National Care Forum warned that the sector is facing the “most acute recruitment and retention crisis” in its history, with more than 110,000 vacancies.<sup>139</sup>
- 3.1.8 Nursing and Health Care Assistants perform similar jobs, also on low wages.<sup>140</sup> They have been able to continue working in the UK. This option was not extended to social care workers/PAs.
- 3.1.9 WeG’s assumption is that young unemployed workers can fill these roles. Their assumption is that it is unskilled work that just anyone can do with little training.
- 3.1.10 DDP living in the community and acting as individual employers for Personal Assistants (PA) were not included in pre-Brexit preparations.
- 3.1.11 WeG failed to make their MAC aware of their existence. DDP campaigners were told in a meeting with the Chair of the MAC that WeG had only alerted them to potential issues with social care workers employed by agencies and had omitted to make them aware of the existence of PA users.<sup>141</sup>
- 3.1.12 Despite the UK Government pledge to match all funding that would have been received from the European Union, the Welsh Government

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<sup>139</sup> [Delahunty, \(2021\). Care sector facing 'most acute recruitment and retention crisis' in its history, not-for-profit organisations warn. \*Thirdsector.com\*, \[online\] 29 September.](#)

<sup>140</sup> Disabled People whose care and support is funded through Continuing Health Care have primarily medical needs as well as social ones.

<sup>141</sup> Meeting between DPAC and MAC on 01.04.2021.

estimated a £772 million loss in funding, with a further £243 loss for rural communities.<sup>142</sup>

3.1.13 In 2021, research showed that Wales was the worst affected country in the UK for loss of funding.<sup>143</sup>

## 3.2 COVID-19

3.2.1 Disability inequality was becoming entrenched before the pandemic. The impacts of the pandemic both exacerbated and were exacerbated by that existing inequality.

3.2.2 In 2018 the EHRC warned that “Britain’s most at-risk groups of people are in danger of being forgotten and becoming trapped in disadvantage...This inequality risks becoming entrenched for generations to come, creating a two-speed society where these groups are left behind in the journey towards a fair and equal country.” These groups consisted of DDP, some ethnic minorities, and children from poorer backgrounds for whom “Prospects... have worsened in many areas of life.”<sup>144</sup>

3.2.3 WeG was not prepared for the pandemic. WeG did not engage with DDP or DDPOs when formulating their response, despite DDP being both most at risk from COVID-19 and worst impacted by measures adopted to contain the pandemic.

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<sup>142</sup> [Rebecca Evans MS \(2022\). Written Statement: Loss of Funding to Wales as a result of the UK Government’s arrangements for replacement EU funding. \[online\] 4 May](#)

<sup>143</sup> [Nation Cymru \(2021\). Wales being worst hit by post Brexit losses of EU funding, research shows. \*nation.cymru\*, \[online\] 15 August](#)

<sup>144</sup> [Equality and Human Rights Commission \[EHRC\], \(2018\) \*Is Britain Fairer? The state of equality and human rights in Britain\*. \[online\], p.5.](#)

- 3.2.4 In their inquiry into DDP’s experiences of the pandemic, WeG’s Women and Equalities Committee found that “While Ministers described their engagement with disabled stakeholders during the pandemic as very positive, open and effective, some disabled people and their organisations felt excluded and ignored.” They exhorted WeG to “consult widely with disabled people and their organisations on ... genuinely effective mechanisms by which disabled people can influence policies and practices which directly affect them.”<sup>145</sup>
- 3.2.5 The intersectional needs of DDP were not considered. For example, Disabled asylum seekers were overlooked except for community initiatives.<sup>146</sup>
- 3.2.6 Disabled people were over-represented among COVID-related deaths, even accounting for age and health factors. Analysis by ONS identifies poverty as a key factor within this as well as care home residency.
- 3.2.7 Official figures record that disabled people accounted for nearly 60% of COVID-related deaths. The true proportion is likely to be higher: DDP made up 17.2% of the study population which is lower than the 22% of disabled people within the UK population.<sup>147</sup>
- 3.2.8 ONS concludes: “This means a sizeable part of the difference in COVID-19 mortality between disabled and non-disabled groups is explained by the

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<sup>145</sup> [WEC \(2020\). \*Unequal impact? Coronavirus, disability and access to services\*. HC 1050, \[online\] 22 December.](#)

<sup>146</sup> [Evidence submitted to our 2022 CRDP shadow report](#)

<sup>147</sup> [Office for National Statistics \[ONS\], \(2021\). Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England: 24 January to 20 November 2020. \[online\] 11 February.](#)

different circumstances in which members of those groups are known to live, such as domains of socio-economic disadvantage.”<sup>148</sup>

3.2.9 The pandemic saw a return to purely medical understanding of risk and “vulnerability” leaving millions at risk from non-medical factors linked to self-isolating that were not considered in planning.<sup>149</sup>

### **Article 19**

3.2.10 The Coronavirus Act 2020 introduced easements to the duties of LAs towards DDP.

3.2.11 Easements under the Care Act 2014 affected duties to assess needs, carry out financial assessments and make support plans. Only eight LAs officially used these powers with only two making use of the most significant easement suspending the duty to meet need. By the end of June 2020 all of them had reversed their decision to operate the easements.<sup>150</sup> Anecdotally, DDP were still left waiting for long periods for assessments.

3.2.12 Under the Act, people detained under the Mental Health Act were exempt from the right to go outside for exercise once a day. The total visiting ban meant ward activities and therapy ceased. Anecdotally, this led to increased bullying, assault, and self-harm and there were no efforts by staff to facilitate virtual contact with friends and family.<sup>151</sup>

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<sup>148</sup> [Office for National Statistics \[ONS\], \(2020\). Coronavirus \(COVID-19\) related deaths by disability status, England and Wales: 2 March to 14 July 2020. \[online\] 18 September.](#)

<sup>149</sup> [TourettesHero, \(2020\). Understanding the Risks. \[online\].](#)

<sup>150</sup> [Carter, C. \(2021\). Government scraps coronavirus provisions allowing councils to suspend key Care Act duties. \*Community Care\*, \[online\] 25 March.](#)

<sup>151</sup> [Evidence submitted for our 2022 CRDP shadow report.](#)

3.2.13 The Coronavirus Act also introduced an easement to the Children and Families Act 2014 which lessened the legal obligations for provision of support for Deaf and disabled children and young people (CYP).

### **Article 27**

3.2.14 Disabled workers were over-represented among redundancies during the pandemic. From July to November 2020, 21.1 per thousand disabled workers were made redundant compared to 13.0 per thousand who are non-disabled.<sup>152</sup>

3.2.15 DDP faced long delays following requests adjustments and a range of other issues with Access to Work after home working began during lockdown.

3.2.16 This prompted the DDPO Inclusion London to write to the Minister for Disabled People urging action to be taken to protect DDP's jobs.<sup>153</sup>

3.2.17 Workers experiencing Long Covid have faced employment discrimination. One in seven survey respondents lost their job because of reasons connected to Long Covid.<sup>154</sup> Given numbers experiencing this, this is a big issue. As of March 2023, an estimated 1.9 million people were experiencing self-reported Long Covid in the UK.<sup>155</sup>

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<sup>152</sup> [ONS \(2021\). Coronavirus and redundancies in the UK labour market: September to November 2020. \[online\]](#)

<sup>153</sup> [Inclusion London \(2020\). Fix problems with Access to Work to protect Disabled people's jobs. Inclusionlondon.org.uk, \[online\] 5 May](#)

<sup>154</sup> [TUC and Long Covid Support \(2023\). Workers' experiences of Long Covid. \[online\] March](#)

<sup>155</sup> [ONS \(2023\). Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK: 30 March 2023. \[online\]](#)

## Article 28

- 3.2.18 In March 2020, WeG introduced a temporary pandemic lift to UC of £20 per week. This was not applied to over 2.2 million legacy benefit claimants, three quarters of whom are DDP.
- 3.2.19 Many of these had significantly increased expenditures due to COVID-19. For example: for the purchase of Personal Protective Equipment for themselves and their Personal Assistants/support workers, through increased energy costs and due to online delivery fees.
- 3.2.20 In a survey of 1,800 disabled benefit claimants more than three quarters (78%) said their financial situation was ‘worse’ compared to at the start of the pandemic; half (52%) were spending ‘significantly more’ on household bills and utilities than they were before the pandemic; 67% were struggling to eat a balanced diet, 67% were struggling to pay bills and just under half (46%) were falling behind on rent or mortgage payments.<sup>156</sup>
- 3.2.21 Personal testimonies shared by legacy benefit claimants included experiences from families unable to wash or do laundry regularly.<sup>157</sup>
- 3.2.22 The explanation was that the uplift was for people who work. This fuelled a view among DDP that WeG does not value their lives.<sup>158</sup>

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<sup>156</sup> [Disability Rights UK \(2021\). Broken benefits system forcing thousands of Disabled people to fall behind on payments and skip meals. \*disabilityrightsuk.org\*, \[online\] 31 August](#)

<sup>157</sup> [Disabled People Against Cuts \(2021\). #20More4All – Why the £20 per week uplift to Universal Credit must be applied to legacy benefits: testimonies, stats & facts. \[online\].](#)

<sup>158</sup> Direct references to disability hostility and feelings that the Westminster Government does not value Deaf and Disabled people’s lives were received in 20 separate responses to the consultation for our 2022 shadow report.

3.2.23 Chancellor of the Exchequer explained in a televised interview that the uplift was intended for those adjusting to loss of income through losing their jobs due to the pandemic.<sup>159</sup> He said:

"The original rationale for doing the temporary uplift in universal credit was to help those on low incomes. People who were in work but whose incomes were going to be affected by the crisis. It's universal credit and working tax credit that are the benefits that capture the vast, vast, vast majority if not all of those people. The legacy benefits don't do that."

3.2.24 Even after the uplift, UC represented just 43.4% of the minimum income required for a decent standard of living.<sup>160</sup> WeG removed the uplift on 30 September 2021, despite widespread opposition including from senior Conservatives and former Secretaries of State for Work and Pensions.<sup>161</sup>

### 3.3 Cost of Living Crisis

3.3.1 DDP are disproportionately impacted by this as we are people more likely to live in poverty with no savings.

3.3.2 The unavoidable extra costs of disability have increased dramatically in recent years.

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<sup>159</sup> *The Martin Lewis Money Show* (2021). [TV programme] ITV, 5 March: 20:30 ; [Money Saving Expert \(2021\). Martin Lewis grills Chancellor Rishi Sunak on self-employed income support, stamp duty, benefits help & more. moneysavingexpert.com, \[online\] 5 March](#)

<sup>160</sup> Without the uplift, UC is just 33.9% of the amount needed for a decent standard of living. [Joseph Rowntree Foundation \(2021\). Planned cuts to Universal Credit will hit incomes of millions of households unable to afford a minimum living standard. \[press release\] 14 July.](#)

<sup>161</sup> [Jones, H. \(2021\). Six ex Tory ministers call for Universal Credit increase to become permanent. Metro, 4 July](#)

- 3.3.3 On average, the extra cost of disability is equivalent to 63% of household income after housing costs. Households with at least one disabled adult or child need an additional £975 a month on average to have the same standard of living as non-disabled households.<sup>162</sup> Updated to account for inflation this rises to £1,122.
- 3.3.4 The average extra costs rise to £1,248 per month where there are two disabled adults in the household and at least two children. And for households with one disabled adult, one non-disabled adult and at least one child, the average extra cost is £634.<sup>163</sup>
- 3.3.5 DDP have an available amount to spend that was about 44% lower than that of other working-age adults, exposing them hugely to the rising cost of essentials.<sup>164</sup> The Resolution Foundation said there was a chasm between the underlying disposable incomes of people with a disability (£19,397 a year) and the non-disabled population (£27,792).
- 3.3.6 Almost half (48%) of DDP said they had to cut back on energy use this winter, compared with almost one-third of non-disabled people.<sup>165</sup>
- 3.3.7 41% of DDP said they could not afford to keep their homes warm, compared with 23% of the non-disabled population.<sup>166</sup>
- 3.3.8 DDPOs and charities have criticised government measures to help those on benefits as inadequate.

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<sup>162</sup> [Scope \(2023\). Disability Price Tag 2023: the extra cost of disability. \[online\]](#)

<sup>163</sup> Ibid.

<sup>164</sup> According to analysis of official figures and a YouGov survey of just under 8,000 working-age adults, more than 2,000 of whom reported a long-term illness or disability. [El Dessouky, O. and McCurdy, C. \(2023\). Costly differences: Living standards for working-age people with disabilities. Resolution Foundation BRIEFING, \[online\] January.](#)

<sup>165</sup> Ibid.

<sup>166</sup> Ibid.

- 3.3.9 About 8 million people will receive £900 in three instalments: £301 made in the spring; a £300 second cost-of-living payment in the autumn; and a third cost-of-living payment of £299 made in spring next year.
- 3.3.10 There will be a further £300 payment for pensioners in winter 2023/24 and more than 6 million disabled people will receive a separate £150 payment as part of the plan.<sup>167</sup>
- 3.3.11 Even with the cost-of-living support payments, a couple with two children, on out-of-work benefits, only have just over half (52%) of what they need for a minimum standard of living.<sup>168</sup>
- 3.3.12 The political crisis has halted the development of the Anti-Poverty Strategy in NI. There is a public funding crisis which is eroding the very fabric of NI society and plunging DDP further into poverty and disadvantage. DDP are making impossible choices between eating and breathing without intervention.

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<sup>167</sup> [McGuinness, R. \(2023\). Charities hit out at 'woefully inadequate' £150 cost of living payment for disabled people. Yahoo!News, \[online\] 22 May](#)

<sup>168</sup> [JRF \(2022\). A Minimum Income Standard for the UK in 2022: summary. \[online\] p.2](#)

## 4. Devolved Issues

### 4.1 Access to Justice

**[See Section 6 for England and Wales]**

#### Northern Ireland

- 4.1.1 In Northern Ireland Barriers exist with respect to reporting crime, and accessing legal advice and legal representation<sup>169</sup>. There is a lack of knowledge within the legal system of how to book sign language interpreters, and the role of interpreters (who have a multi-faceted communication role between legal professionals and deaf people)<sup>170</sup>.
- 4.1.2 There are challenges associated with the identification of disability when DDP engage with Justice System and are held in custody<sup>171</sup>.

#### Scotland

- 4.1.3 DDP are more likely to say they have experienced a civil law problem<sup>172</sup>, but there are still barriers to getting advice, for example,

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<sup>169</sup> Department for Communities (2020). [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#), [online] p.98

<sup>170</sup> Byrne, B., Elder, B. and Schwartz, M. (2021). [Enhancing Deaf People's Access to Justice in Northern Ireland: Implementing Article 13 of the UN Convention on the Rights of Persons with Disabilities](#), *Scandinavian Journal of Disability Research*, 23(1), pp.74–84.

<sup>171</sup> McKinnon, I. and Finch, T. (2018). [Contextualising health screening risk assessments in police custody suites – qualitative evaluation from the HELP-PC study in London, UK](#). *BMC Public Health*, 18, 393.

<sup>172</sup> Scottish Government (2020). [Legal Aid Reform in Scotland Consultation – Scottish Government Analysis](#) [online]

lack of availability, inaccessible information and buildings, not being listened to, costs, lack of legal aid and discriminatory attitudes. Costs associated with reasonable adjustments are not met by legal aid. For example, BSL users requiring the use of interpreters when dealing with lawyers.

## 4.2 Cost of Living Crisis

### England (WeG)

4.2.1 A quarter of DDP responding to a cost of living survey have had to use a food bank or have relied on others to get food while 68% have had to change the type of foods that they usually buy or what they eat because of low income.<sup>173</sup>

4.2.2 A third of respondents cannot afford to pay all their bills and 31% are borrowing money to afford this.<sup>174</sup>

### Northern Ireland

4.2.3 The escalating cost of living emergency has increased the abuse and exploitation of DDP who have been subject to cuckooing and exploitation for access to medication.

4.2.4 Deaf and disabled children and their families are more likely to live in poverty than their non-disabled counterparts<sup>175</sup>. DDP are 50% more

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<sup>173</sup> [Greater Manchester DDP's Panel \(2022\). Greater Manchester Big Disability Survey 2022: Cost of Living. \[online\]](#) p.16

<sup>174</sup> Ibid. p.16

<sup>175</sup> Child Poverty Alliance (2014). [Beneath the Surface](#) [online]

likely to live in poverty and disadvantage than those who do not have a long-standing illness.<sup>176</sup>

- 4.2.5 Households with one or more d/Deaf and disabled members faced large and disproportionately negative impacts from tax and benefit changes made between 2010 and 2018.<sup>177</sup>
- 4.2.6 78% of DDP not in receipt of disability social security benefits come from households experiencing the highest levels of deprivation.
- 4.2.7 According to the Trussell Trust Foodbank Network, which operates 36 foodbanks across Northern Ireland, more than 62% of working age DDP are referred to their network for support.<sup>178</sup> 23% of households with a disability were losing more than a quarter of their income on repaying debt or loans, compared to 14% among households not affected by disability whilst 41% of DDP were in debt to WeG's UK Department of Work and Pensions (DWP).<sup>179</sup>
- 4.2.8 The Trussell Trust also found that even if some people were successful in applying for and receiving disability benefits such as DLA and PIP, for many it was not enough to prevent hardship and material deprivation in many households indicating that disability benefits, for those fortunate enough to meet the threshold for entitlement, was not sufficient to meet the extra costs associated with disability and ill health.<sup>180</sup>

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<sup>176</sup> UKIM (2018). [Progress on disability rights in the United Kingdom](#) [online] p.21

<sup>177</sup> EHRC (2020). [The cumulative impact of tax and welfare reforms](#) [online] p.15

<sup>178</sup> BBC (2021). [Coronavirus: Food bank need for NI children 'at historic level' \*bbc.co.uk\*, \[online\] 22 April](#)

<sup>179</sup> The Trussell Trust (2021). [The State of Hunger: it's not right that DDP are being forced to turn to food banks](#)

<sup>180</sup> Ibid.

- 4.2.9 DDP have been unable to access cost of living payments issued by the Department for Communities.
- 4.2.10 The political crisis has halted the development of the Anti-Poverty Strategy.
- 4.2.11 There is a public funding crisis which is eroding the very fabric of Northern Ireland society and plunging DDP further into poverty and disadvantage.
- 4.2.12 DDP are making impossible choices between eating and breathing without intervention.

### Scotland

- 4.2.13 Despite the Scottish Government uprating all Scottish benefits in line with inflation for 2023-24,<sup>181</sup> they remain inadequate and need to be further increased to address the rising cost of living which disproportionately impacts upon DDP who face additional impairment related costs.<sup>182</sup>
- 4.2.14 In particular, energy costs for powering essential equipment that some DDP need such as hoists, beds, breathing equipment, dialysis machines, powered chairs and monitors were already expensive.

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<sup>181</sup> [Supporting documents – Social Security \(Scotland\) Act \(2018\): Devolved Social Security Assistance, Uprating for Inflation – A report in fulfilment of section 86A: Duty to consider effects of inflation – gov.scot \(www.gov.scot\)](#)

<sup>182</sup> [Disability Price Tag 2023: the extra cost of disability | Disability charity Scope UK](#)

- 4.2.15 Now some households including a disabled person are having to make choices about using this essential equipment, heating their home, or eating properly.<sup>183</sup> And face hospitalisation if their health deteriorates.
- 4.2.16 Take up of devolved benefits in Scotland is inconsistent.<sup>184</sup>
- 4.2.17 The current cost of living crisis that is disproportionately impacting DDP<sup>185</sup> comes after a decade of austerity that has eroded the safety net for DDP, a pandemic response that did not prioritise our human rights, and an approach to economic recovery that does not value us.
- 4.2.18 In a survey of DDP,<sup>186</sup> over 75% of respondents reported that they were ‘going without or cutting back’ on essentials like food, heating and energy, as well as medication and personal hygiene items. Respondents reported being fearful of hospitalisation or dying at home.
- 4.2.19 The cost of living crisis is also having consequences for DDP’s right to live in a home of their choosing. Increasing costs for using medical equipment and assistive technology is forcing some DDP to make stark choices about whether and how often they use such equipment.<sup>187</sup> In some cases DDP are being forced to choose between ‘eating or

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<sup>183</sup> [Inclusion-Scotland-Briefing-Disabled-People-Poverty-and-the-Cost-of-Living-Crisis-Version-1-November-22nd.pdf \(inclusionScotland.org\)](#)

<sup>184</sup> [Take-up rates of Scottish benefits: October 2022 – gov.scot \(www.gov.scot\)](#)

<sup>185</sup> [ONS \(2022\). Impact of increased cost of living on adults across Great Britain: June to September 2022. \[online\] 25 October](#) The Office for National Statistics found that DDP in the UK were more likely than non-DDP to be finding it difficult to afford energy bills, rent or mortgage payments, and more likely to report being behind with payments.

<sup>186</sup> [Cost of living crisis hits DDP hard- New Report Published. – Inclusion Scotland](#)

<sup>187</sup> [Thousands of DDP tell MPs: Cost-of-living crisis is affecting our health – Disability News Service; Cost of living crisis hits DDP hard- New Report Published. – Inclusion Scotland](#)

breathing’,<sup>188</sup> putting their health at risk with the inevitable consequence of being forced to go into hospital or residential care.

- 4.2.20 The Scottish Government continues to take measures to mitigate the impact of the benefit cap, including through increasing funding for discretionary housing payments which support people with housing and living costs.<sup>189</sup>
- 4.2.21 Despite providing two cost of living payments of £150 to DDP, this does not compensate for the additional pressure on household budgets created by the delay in benefit uprating. It also fails to take into account the differences in additional costs faced by various DDP, including those in rural communities whose disability and location may intersect to create vastly inflated living costs.<sup>190</sup>

## Wales

- 4.2.22 Poverty is an overwhelming barrier, one survey respondent described poverty as a “fact for DDP in Wales”.<sup>191</sup> Welfare is mostly reserved, but the Welsh Government has competency over some benefits which are distributed by local authorities, such as direct payments and local housing allowance (LHA).<sup>192</sup>
- 4.2.23 Most policy interventions in Wales have been in the form of short-term economic support. The cost-of-living fund gave a £150 cost-of-

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<sup>188</sup> [‘Eating or breathing’: energy costs force stark choices on DDP | UK cost of living crisis | The Guardian](#)

<sup>189</sup> [Helping families with their living costs – gov.scot \(www.gov.scot\)](#)

<sup>190</sup> [Why DDP are at the centre of the cost-of-living crisis | Disability charity Scope UK; One-off payment not enough to end cost of living crisis – DR UK | Disability Rights UK](#)

<sup>191</sup> “Poverty is a fact for DDP 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

<sup>192</sup> [Welsh Government, \(2019\). Local Housing Allowance \[online\] 7 March](#)

living payment to certain DDP, distributed by local authorities.<sup>193</sup> This payment however was poorly communicated, one disabled person we spoke to in 2022 told us they had received the payment into their bank account with no information about what the payment was or how they had received it.

- 4.2.24 Respondents to Disability Wales surveys in 2022 and 2023 also criticised the payment for not going far enough, one survey respondent told us that it was useful support for a month but was not adequate financial support for a long-term crisis.
- 4.2.25 The Winter Fuel Allowance payment was doubled to £200 in 2021 and in 2022 the Welsh Government announced the extension of its eligibility criteria to include more social security recipients, overall allowing a further 200,000 households to apply.<sup>194</sup> This scheme had the highest level of awareness from DDP we surveyed, with 65 of the 74 respondents to a Disability Wales survey having heard of the fund.
- 4.2.26 Surveys conducted by Disability Wales in 2022 and 2023 on the cost-of-living crisis showed low levels of knowledge of the support services that had been made available. The Welsh social security Discretionary Assistance Fund (DAF), which is a grant given to people for essential costs in emergency situations or who need funds to live independently,<sup>195</sup> had relatively low levels of awareness, in 2023 only 30 of the 74 respondents to the survey having prior knowledge of the fund.

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<sup>193</sup> [Welsh Government \(2022\). £150 cost-of-living payments arrive with more than 300,000 homes \[online\] 12 May](#)

<sup>194</sup> [Welsh Government \(2022\). Welsh Government Winter Fuel Support scheme extended to more than 400,000 low-income households after 90m investment \[online\] 19 July](#)

<sup>195</sup> [Welsh Government \(n.d.\) Discretionary Assistance Fund \(DAF\) \[online\]](#)

4.2.27 The Welsh Government supplied a £1 million fund for warm banks in September 2022, however, we feel this move was not well thought through. Many DDP that Disability Wales spoke to have criticised the warm banks or told us that they were not able to access these services as they could not access transportation to them or did not want to go outside into the cold to be able to get there.<sup>196 197</sup>

## 4.3 COVID-19

### England (WeG)

4.3.1 39,017 people died in care homes in England between 10 April 2020 and 31 March 2021.<sup>198</sup> It is estimated that over 4,000 additional deaths occurred before 10 April.<sup>199</sup>

4.3.2 A medical approach to disability determined whether DDP lived or died during the pandemic. WeG declined to provide national guidance that would guarantee DDP the same rights to life sustaining treatment as non-DDP.<sup>200</sup>

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<sup>196</sup> Respondent to 2023 Disability Wales survey

<sup>197</sup> Participant in 2023 Disability Wales focus group

<sup>198</sup> [CQC \(2021\). CQC Death Notifications from Care Homes. \[online\], 21 July.](#)

<sup>199</sup> [Sabin, L. \(2021\). England's COVID care home deaths could be thousands higher than official figures, say providers. \*Independent\*, 1 August.](#)

<sup>200</sup> [Pring, J. \(2020\). Coronavirus: Hancock refuses to publish treatment guidance. \*Disability News Service\*, 23 April.](#)

4.3.3 An independent inquiry was commissioned into unlawful use of Unlawful use of blanket Do Not Attempt Cardio-Pulmonary Resuscitation Orders (DNACPRs) on the medical notes of DDP.<sup>201</sup>

### **Article 19**

4.3.4 The government only published COVID guidance for DDP on direct payments who employ their own PA's – a group of around 70,000 DDP in England – more than five weeks after it had published guidance for the wider social care sector and only as the result of lobbying by those affected.<sup>202</sup>

4.3.5 Many direct payment users were unable to access personal protective equipment in the early months of the pandemic.<sup>203</sup> They also had to pay for this themselves despite spiralling costs.

4.3.6 During the pandemic, social care support was reduced or suspended.

4.3.7 Many PAs could not go to work in DDP's own homes because of lack of access to PPE or because they were self-isolating.

4.3.8 Anecdotally, we heard that LAs would not increase funding to help DDP requiring extra support due to lockdown conditions.

4.3.9 This contributed to the 50% rise in deaths among DDP living in the community in receipt of social care support from April 2020 – March

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<sup>201</sup> [CQC \(2021\). Protect, respect, connect – decisions about living and dying well during COVID-19. \[online\].](#)

<sup>202</sup> Given a similar situation with the Migration Advisory Committee where they were not even aware of the existence of this group of people, it seems likely that they have come completely off WeG's radar as a consequence of complete derogation of WeG's article 19 responsibilities.

<sup>203</sup> [Pring, J. \(2020\). Coronavirus: Kendall promises to challenge minister over lack of PA guidance. Disability News Service, \[online\] 16 April](#)

2021. Of the 25,000 deaths, data suggests only 8.7% were COVID-19 related.<sup>204</sup> There was a nearly 50% increase in deaths from thirst unrelated to COVID.<sup>205</sup>

4.3.10 Even after WeG dropped the provision for easements to the social care duties of LAs from April 2021, DDP nevertheless continued experiencing long assessment delays, difficulties contacting social services and reduced support provision from care providers.<sup>206</sup>

4.3.11 DDP in residential homes were subject to 14 days self-isolation if they left the home for contact with friends or family.<sup>207</sup> Providers were not clear on guidelines and families were prevented from visiting despite this causing extreme distress to people with learning difficulties/who are autistic.<sup>208</sup>

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<sup>204</sup> [Gayle, V., Hamada, R., Boutaud, R. \(2021\). Revealed: Thousands more deaths in home care during pandemic. \*The Bureau of Investigative Journalism\*, \[online\] 10 May.](#)

<sup>205</sup> From January – July 2020, a total of 345 non-COVID patients died of thirst across all settings, a 48 per cent –increase on the previous five-year average of 232. [Nelson, N. \(2020\). Thirst killed 345 non-COVID patients in hospitals and care homes during first lockdown. \*Mirror\*, \[online\] 13 December.](#)

<sup>206</sup> [Inclusion London \(2020\). Abandoned, forgotten and ignored: the impact of the coronavirus pandemic on DDP. \[online\] June](#)

<sup>207</sup> [Evidence for 2022 shadow report received from Access Social Care. ; evidence for 2022 shadow report received from Regard](#)

<sup>208</sup> In one case study, a provider insisted on 2:1 staffing to facilitate a family visit so that a woman with learning difficulties could be physically restrained if she broke social distancing rules by attempting to hug her family. [Evidence for 2022 shadow report received from Access Social Care.](#)

4.3.12 Support services for CYP and their families stopped or reduced during the pandemic and were slow to return.<sup>209</sup>

### **Article 27**

4.3.13 Legal protections for Disabled workers ended on 31 March 2021 when WeG announced an official end to shielding despite COVID rates still being high.<sup>210</sup>

4.3.14 Many employers had not respected DDP's right to life before this. Research by disability charity Scope found that 22% of disabled workers faced having to choose between going to their place of work and quitting their job.<sup>211</sup>

### **Article 33**

4.3.15 Official communications about the pandemic were confusing and not made available in accessible formats. WeG refused to provide BSL interpretation for televised public briefings (which Scotland and Welsh

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<sup>209</sup> DCP (2021). *Then There Was Silence*. [online]. Available at:

<https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/10/Then-There-Was-Silence-Full-Policy-Report-10-September-2021.pdf>

<sup>210</sup> DPAC and Black Activists Rising Against Cuts (2021). Joint Press Statement on Safety at Work after the ending of Shielding. [press release] 31 March. Available at:

<https://dpac.uk.net/2021/03/joint-press-statement-on-safety-at-work-after-the-ending-of-shielding/> Accessed on: 15.03.22

<sup>211</sup> Faragher, J. (2020). A fifth of disabled workers had work from home requests turned down during pandemic. *Personnel Today*, 23 November. Available at:

<https://www.personneltoday.com/hr/a-fifth-of-disabled-workers-had-covid-work-from-home-requests-turned-down/> Accessed on: 15.03.22

Governments put in place) until forced by a high court ruling<sup>212</sup>. At this point there was only one public briefing left.

### Northern Ireland

- 4.3.16 The degree to which the emergency response of the Executive to the Covid-19 crisis included people with disabilities and addressed their needs has been called into question by DDP and by the Equality Commission for Northern Ireland.<sup>213</sup>
- 4.3.17 Initial guidance from government agencies was not attuned to the needs of persons with learning disabilities and their living situations; particularly for those in supported living arrangements rather than residential homes. The guidance from different agencies was contradictory and had not been developed through consultation with organisations and personnel with the necessary expertise. Revised guidance has been made available, but a lack of consultation remains an issue beyond Covid-19.<sup>214</sup>
- 4.3.18 The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of wave one deaths due to Covid-19 which showed that DDP were 40% more likely to die of Covid-19.<sup>215</sup> There are

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<sup>212</sup> [BBC News \(2021\). COVID: Deaf woman wins claim over lack of sign language at briefings. \*bbc.co.uk\*, \[online\] 28 July.](https://www.bbc.com/news/health-57411111)

Judgment available here: <https://www.judiciary.uk/wp-content/uploads/2021/07/R-on-the-application-of-Katherine-Rowley-v-Minister-for-the-Cabinet-Office.pdf>

<sup>213</sup> ECNI (2020). [People with disabilities must not be left behind by response to COVID-19](#)

<sup>214</sup> ARC (NI) (2020). [A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland](#), p.8

<sup>215</sup> NISRA (2021). [Covid-19 Deaths and Equality – Wave One](#)

concerns regarding the inappropriate use of Do Not Resuscitate Orders.<sup>216</sup>

## Scotland

- 4.3.19 Initial Scottish Government guidance for doctors making treatment decisions during the pandemic was based on blanket approaches to age, medical conditions or disability was discriminatory.<sup>217 218</sup>
- 4.3.20 The UK and Scottish Governments were underprepared for the pandemic.<sup>219 220</sup> Limited plans were in place to protect people at risk and to ensure essential services could continue to operate.
- 4.3.21 The Third sector was vitally important in providing material and emotional support and bringing attention to the impact of pandemic responses on the groups they represent.<sup>221</sup>

## Cuts to services

- 4.3.22 Cuts to social care during the pandemic were devastating for DDP.<sup>222</sup> Despite being three years on from the start of the pandemic not everyone's social care package has been returned to pre-pandemic

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<sup>216</sup> BBC (2021). [People with learning disabilities 'living a nightmare'](#) This article includes Amanda Paul's contribution to the Disabled People's Parliament in which Amanda recounts her own experience with respect to Do Not Resuscitate Orders.

<sup>217</sup> [Equality watchdog says virus guidance discriminates \(healthandcare.scot\)](#)

<sup>218</sup> [Scottish Human Rights Commission \(2020\). COVID-19 Guidance: Clinical Advice \[online\]](#)

<sup>219</sup> Audit Scotland (2021). [Lessons to be learned from pandemic response](#)

<sup>220</sup> National Audit Office (2021). [The government's preparedness for the COVID-19 pandemic: lessons for government on risk management](#)

<sup>221</sup> University of Glasgow (2020). [Scotland in lockdown](#)

<sup>222</sup> [Rights-At-Risk-Main-Report.pdf \(inclusionScotland.org\)](#); ; Scottish Human Rights Commission (2020) [COVID-19, Social Care and Human Rights: Impact Monitoring Report](#)

levels, and changes in circumstances have not been assessed or addressed. The full extent of the impact on care packages is not known because of inconsistent data collection.

- 4.3.23 DDP lost access to health services during pandemic and there is concern about deteriorating health with people in Scotland and across the UK reporting their health has got worse.<sup>223</sup>
- 4.3.24 The pandemic has had a devastating impact on DDP’s mental health.<sup>224</sup> DDP with and without pre-existing mental health conditions reported that the experience of lockdown was extremely stressful and dealing with a range of challenging issues including: the loss or reduction of vital social care support, the loss of health care, having to shield, anxiety around potentially being denied access to life-saving treatment, taking on new or increased caring responsibilities, having to work in high-risk occupations and homeschooling children.
- 4.3.25 We found that DDP were experiencing a mental health crisis – people told us they could not cope and a number reported that they were suicidal.<sup>225</sup>
- 4.3.26 Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

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<sup>223</sup> Inclusion Scotland (2020) [Rights at risk – Covid-19, DDP and emergency planning in Scotland](#); Glasgow Disability Alliance (2020) [Supercharged: A Human Catastrophe Inequalities, Participation and Human Rights before, during and beyond COVID19](#); Office for National Statistics (2020) [Coronavirus and the social impacts on DDP in Great Britain: September 2020](#); Office for National Statistics (2021) [Coronavirus and the social impacts on DDP in Great Britain: February 2021](#)

<sup>224</sup> [ONS – Coronavirus and depression in adults in Great Britain](#)

<sup>225</sup> Inclusion Scotland (2020) [Rights at risk – Covid-19, DDP and emergency planning in Scotland](#); Glasgow Disability Alliance (2020) [Supercharged: A Human Catastrophe Inequalities, Participation and Human Rights before, during and beyond COVID19](#)

- 4.3.27 There is evidence that DDP and older people may have been targeted for DNAR orders during the pandemic, including people with dementia and people with learning disabilities. There is an absence of official data on numbers of DNAR orders made.<sup>226</sup>
- 4.3.28 The independent inquiry into Covid-19 pandemic in Scotland will investigate use of DNARs.<sup>227</sup>

### **Lifting of Covid-19 restrictions/protections**

- 4.3.29 Social isolation continues to be an issue for DDP left behind as Covid-19 protections have been lifted, with some DDP and their immediate carers effectively still shielding, without the support that was previously available such as universal testing, and community-based support.
- 4.3.30 This has been exacerbated by confusion over vaccinations and treatments with those eligible for treatments not always eligible for additional vaccinations and vice versa. In addition, those receiving vaccinations did not always benefit from protections due to being immuno-suppressed.
- 4.3.31 On 16 May 2023, guidance to wear face masks in healthcare settings was withdrawn in Scotland. This was met by outcry from DDP at high risk and was done with apparently little/no consultation.

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<sup>226</sup> See – Daily Record (2020) [Scots mum 'gobsmacked' after medics ask if daughter, 12, with cancer should be resuscitated](#); The Courier (2020) [Coronavirus: Family anger after Dundee doctor asks 86-year-old to accept 'do not resuscitate' request](#); Herald Scotland (2020) [Coronavirus in Scotland: Health board denies 'do not resuscitate' policy on Covid-19 patients](#); Deaf Action (2021) [Deaf man given DNR order without his consent](#); Inclusion Scotland (2020) [Rights at risk – Covid-19, DDP and emergency planning in Scotland](#)

<sup>227</sup> Scottish Government (2021), [Covid-19 Inquiry](#)

- 4.3.32 In the first year of the pandemic DDP's employment rate fell.<sup>228</sup> Although the full impact of the pandemic on employment is yet to become clear, evidence shows:
- DDP are more likely to have worked in sectors hardest hit by the pandemic.<sup>229</sup>
  - 40% of UK DDP reported being furloughed.<sup>230</sup> UK DDP reported feeling at greater risk of redundancy.<sup>231</sup>
  - Stigma and discrimination towards disabled workers appear to have increased during the pandemic.<sup>232</sup>
- 4.3.33 The move to working from home has benefited many DDP who have been asking for such adjustments for many years.
- 4.3.34 There is growing evidence that the Covid-19 crisis has pushed more families into poverty.<sup>233</sup>
- 4.3.35 DDP were more likely than non-DDP to say their finances had been negatively impacted during the pandemic and were worried about

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<sup>228</sup> Scottish Government (2021) [Scotland's Labour Market: People, Places and Regions – Statistics from the Annual Population Survey 2020/21](#) – (April 2020-March 2021).

<sup>229</sup> Scottish Government (2020) [DDP in the labour market in Scotland](#); House of Commons Library (2022) [Coronavirus, impact on the labour market](#)

<sup>230</sup> Leonard Cheshire (2020) [Locked out of the labour market The impact of Covid-19 on disabled adults in accessing good work – now and into the future](#)

<sup>231</sup> Citizens Advice (2020) [An unequal crisis](#)

<sup>232</sup> Leonard Cheshire (2020) [Locked out of the labour market The impact of Covid-19 on disabled adults in accessing good work – now and into the future](#)

<sup>233</sup> See for example: Child Poverty Action Group (2020) [Poverty in the pandemic: The impact of coronavirus on low-income families and children](#); IPPR (2020) [Covid-19: How are families with children faring so far?](#); JRF (2020) [Poverty in Scotland 2020](#)

accumulating more debt.<sup>234</sup> This has been exacerbated by the cost of living crisis.

## Wales

- 4.3.36 Following the publication of the Locked-Out report, which heavily criticised the Welsh Government's response to the coronavirus pandemic, a Disability Rights Taskforce has been established.

## Article 19

- 4.3.37 The Coronavirus Act (Commencement No 1) (Wales) Regulations 2020<sup>235</sup> caused the suspension of key services of the Social Services and Wellbeing (Wales) Act, with exceptions for protecting an adult from abuse, neglect or risk of abuse or neglect.
- 4.3.38 As highlighted in the Locked-Out report, unlike in England for the Care Act 2014, there were no given requirements to not breach the European Convention on Human Rights in this legislation.
- 4.3.39 DDP in series of focus groups held in 2021 told us of the impact, one disabled person we spoke to was told that maintenance work on their mobility equipment was not a priority, leaving them unable to leave their bed for over 24 hours.<sup>236</sup>

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<sup>234</sup> Scottish Government (2020) [Coronavirus \(COVID-19\): impact on wellbeing](#); Family Fund (2021) [The impact of COVID-19 – A year in the life of families raising disabled and seriously ill young children Scotland Findings – March 2021](#)

<sup>235</sup> [Welsh Government \(2020\) The Coronavirus Act 2020 \(Commencement No. 1\) \(Wales\) Regulations 2020 \[online\] 26 March](#)

<sup>236</sup> Participant in 2021 Disability Wales focus group

## **Article 27**

- 4.3.40 DDP told us in 2021 that a move to remote working was beneficial for keeping them in employment.<sup>237</sup> The Welsh Government established “Smart Working: 4.3.41 The Remote Working Strategy for Wales” to encourage remote working.
- 4.3.42 Although primarily targeted towards climate change prevention, the policy specifically sets out that disabled workers should not be expected to give up reasonable adjustments while working from home.<sup>238</sup>

## **4.4 Disability Narratives and Hate Crime**

### **England (WeG)**

- 4.4.1 Disability hate crime in London soared by 20% in 2019/2020 with around half classified as violence.<sup>239</sup> One in four DDP feel unsafe to

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<sup>237</sup> Respondents to 2021 Disability Wales survey

<sup>238</sup> [Welsh Government \(2022\) Smarter working: a remote working strategy for Wales \[online\] 25 May](#)

<sup>239</sup> [Clarke, H. \(2020\). Disability hate crime rates soar in Hackney. \*Hackney Gazette\*, \[online\], 6 November.](#)

travel on public transport.<sup>240</sup> Only one in 62 cases of disability hate crime received a charge in 2019 – 2020.<sup>241 242</sup>

- 4.4.2 In evidence submitted for our 2022 CRDP shadow report we heard anecdotally about stereotypes of DDP as “frauds” now pervading workplaces and associated bullying by managers and colleagues of DDP when needing/asking for reasonable adjustments.<sup>243</sup>

### **Northern Ireland**

- 4.4.3 Disability hate crime has increased by 16% in 2020/2021, according to the Police Service Northern Ireland (PSNI)<sup>244</sup>. There is no specific hate crime legislation in Northern Ireland for DDP or for people with other characteristics protected under equality law.

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<sup>240</sup> Due to negative attitudes from other passengers. [Coffey, H. \(2018\). One in four DDP don't use public transport due to negative attitudes from other passengers, new research finds. Independent, \[online\] 10 October](#)

<sup>241</sup> [Leonard Cheshire \(2020\). Reports of violent disability hate crime continue to rise as number of police charges fall again. \[press release\], 8 October](#)

<sup>242</sup> DDPOs supporting victims report poor responses from the Metropolitan Police across London which reflects experiences reported across the UK. [Inclusion London \(2021\). Poor Police Response. \[online\]](#)

<sup>243</sup> Inclusion London (2022). [Westminster Government Civil Society Shadow Report: Annex A – Our Voices. \[online\] March](#) pp.25 – 26

<sup>244</sup> PSNI (2021): [Incidents and Crimes with a Hate Motivation Recorded by the PSNI: Update 30<sup>th</sup> June 2021](#)

## 4.5 Employment

### Employment – England (WeG)

- 4.5.1 A 2017 report found that bureaucratic incompetence and obstructionism had caused the scheme to become, in many respects, unfit for purpose.<sup>245</sup>
- 4.5.2 The minister for DDP has pledged to carry out a “root and branch” review of the government’s Disability Confident employment scheme, following a decade of criticism from disabled campaigners.<sup>246</sup> Individual organisations involved in the scheme have been responsible for proven cases of disability discrimination. The scheme has not led to tangible improvements in employment outcomes for DDP.

### Employment – Northern Ireland

- 4.5.3 In 2020 the disability employment rate gap in NI was 42.2 percentage points (pps), compared to 27.9pps for the whole of the UK. Since 2014, the disability employment gap has consistently been higher in Northern Ireland than the rest of the UK.<sup>247</sup>
- 4.5.4 Trade Union Congress (TUC) assert that the Disability Pay Gap is linked to unlawful discrimination, structural barriers, and negative attitudes.<sup>248</sup>

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<sup>245</sup> [Hale, C. \(2017\). \*Barriers to Work\*. Inclusion London, \[online\].](#)

<sup>246</sup> [Pring, J. \(2023\). Time for ‘root and branch’ review of Disability Confident, minister admits. Disability News Service, \[online\] 4 May.](#)

<sup>247</sup> <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-disability-within-northern-ireland-labour-market-2022.pdf>, para 5.1 page 29

<sup>248</sup> TUC (2020): [Disability pay and employment gaps 2020](#) (accessed 1 February 2022).

4.5.5 Figures for 2022 demonstrate that DDP in NI earn £1.90 per hour less than non-DDP, meaning that DDP earn £3458 less per year than non-DDP and therefore the disability pay gap in NI is 18%.

4.5.6 Disabled women earn £1.70 per hour less than disabled men.<sup>249</sup>

4.5.7 In addition:

- a higher proportion of DDP are in part time work. Part-time work, particularly in the private sector is paid less per hour than full-time work;
- DDP are over represented in lower paid jobs including caring and leisure, sales, customer services, and other services;
- DDP are under-represented in senior and managerial roles;
- some DDP leave education earlier than non-DDP;# when DDP have the same qualifications the pay gap persists.<sup>250</sup>
- when DDP have the same qualifications the pay gap persists.<sup>251</sup>

4.5.8 ESF has been the primary source of funding for employment projects for DDP in NI. The funding will cease in March 2022. Finance Minister Conor Murphy allocated £26.5mn of Covid-19 funding to extend the ESF programme until the end of March 2023. This programme has now ended. The UK Shared Prosperity Programme offers £20mn funding less than ESF leaving the region at severe disadvantage.

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<sup>249</sup> <https://www.tuc.org.uk/news/non-disabled-workers-paid-17-more-disabled-peers-tuc>

<sup>250</sup> TUC (2020). [Disability pay and employment gaps 2019](#)

<sup>251</sup> TUC (2020). [Disability pay and employment gaps 2019](#)

## Employment – Scotland

- 4.5.9 DDP continue to face significant and interlinked barriers to entering and staying in employment including, having lower educational attainment than their peers,<sup>252</sup> prejudice and negative attitudes in workplaces,<sup>253</sup> lack of career progression, inflexible working practices, lack of support in the workplace and failure to make reasonable adjustments.<sup>254</sup>
- 4.5.10 Fair Start Scotland is Scotland’s devolved employment support service, which aims to help people to prepare for and enter sustainable employment. However, only 32% of DDP who joined the programme started work and just 23% stayed in work for 3 months, 19% for 6 months and 14% for 12 months.<sup>255</sup>
- 4.5.11 The service does not address the specific challenges faced by people with learning disabilities and the take up amongst this group has been low.<sup>256</sup>
- 4.5.12 No One Left Behind funding (Scottish Government’s strategic partnership approach with local government) should be used for national and local co-design with DDP and DDPOs of new accessible

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<sup>252</sup> Scottish Government (2023) [Summary Statistics for Attainment and Initial Leaver Destinations, No. 5: 2023 Edition](#) [online] 28 February – e.g. In 2021/22, only around a third of disabled pupils (35%) left school with at least one higher (grade A-C), compared to almost two thirds (62%) of non-disabled pupils.

<sup>253</sup> [Kumar, S. and Provost, C. \(2022\). Ableism and the Labour Market. Association of Disabled Professionals \[online\] June ;](#)

<sup>254</sup> [Disabled workers’ experiences during the pandemic | TUC ; Ending Poverty and Removing Barriers to Work for DDP in Glasgow beyond Covid-19 • Glasgow Disability Alliance \(gda.scot\) ; Response 343474598 to Disabled employment gap inquiry – Scottish Parliament – Citizen Space](#)

<sup>255</sup> [Scotland’s Devolved Employment Services: Statistical Summary \(www.gov.scot\)](#)

<sup>256</sup> [Learning-disabilities-employment-report-final.pdf \(fraserofallander.org\)](#)

employability support that is specifically targeted at disabled job seekers. Funding opportunities for employability support must to be opened up to more DDPOs which can provide disability competent support.

4.5.13 In December 2022, the Scottish Government published a Fair Work Action Plan – it brings together the actions (which were previously a stand alone action plan) to support DDP into work, with actions for other groups.<sup>257</sup>

4.5.14 There continue to be intersectional barriers to DDP entering and staying in employment including for disabled women<sup>258</sup>, disabled young people<sup>259, 260</sup> and DDP from ethnic minorities<sup>261</sup>.

### **Employment – Wales**

4.5.15 The Disability Action Plan for Apprenticeships set out a three-year plan for supporting DDP to take up apprenticeships as a way of training and entering the workforce.<sup>262</sup> Since its publication in 2018, we have not seen any follow up information on the success of the scheme.

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<sup>257</sup> [Fair Work action plan: becoming a leading Fair Work nation by 2025 – gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/fair-work-action-plan-2022/pages/1-10.aspx)

<sup>258</sup> Close the Gap – [Response 866074028 to Disabled employment gap inquiry – Scottish Parliament – Citizen Space](#)

<sup>259</sup> Scottish Government (2021) [Fairer Scotland for DDP: Employment action plan progress report, year 2](#)

<sup>260</sup> Institute for Fiscal Studies (2020) [Sector shutdowns during the coronavirus crisis: which workers are most exposed?](#)

<sup>261</sup> Scottish Government (2021) [DDP in the labour market](#)

<sup>262</sup> [Welsh Government \(2018\) Inclusive Apprenticeships: Disability Action Plan for Apprenticeships 2018-21 \[online\] 3 December](#)

- 4.5.16 As set out in Action on Disability: A Framework for Independent Living and the Employment and Skills Plan, the Welsh Government has created the role of “DDP’s Employment Champion”, which seeks to work within a network of partners to improve employment opportunities for DDP.<sup>263</sup> <sup>264</sup> The Disability Rights Taskforce has created a specific working group to explore the topic of DDP and employment.<sup>265</sup>
- 4.5.17 The Welsh Government has committed to expanding the “Communities for Work” programme, which since 2015 has supported 41,000 “individuals with complex barriers.” They have pledged to double the original £12 million budget; the Employment and Skills Plan confirms DDP continue to be a key group targeted by programs such as Communities for Work.<sup>266</sup>

## 4.6 Engagement, Monitoring and Data

### Engagement, monitoring and data – England (WeG)

- 4.6.1 WeG does not collect or centrally hold data relevant to article 19 rights. In order to research the social care/independent living support situation in England it is necessary to submit Freedom Of Information requests to all 152 LAs. LAs avoid responding to inconvenient

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<sup>263</sup> [Welsh Government \(2023\) Vacancy – DDP’s Employment Champion x4](#)

<sup>264</sup> [Steve McNally \(2021\) Network of DDP’s Employment Champions Announced. \*Business News Wales\*, \[online\] 26 March](#)

<sup>265</sup> [Hutt, J \(2023\) \*Written Statement: Update on the Disability Rights Taskforce\*, 29 March 2023](#)

<sup>266</sup> [Welsh Government \(2022\). \*Stronger, fairer, greener Wales: a plan for employability and skills\*. \[online\] 8 March](#)

questions and although this can be challenged, it is a lengthy process to go through for multiple FOIs.

- 4.6.2 Although chances for DDPOs to meet with and express views to WeG have increased since 2016, meaningful input into fundamental areas affecting our lives such as those related to the special inquiry are still lacking. The bigger picture is one where DDP are increasingly marginalised and unheard.
- 4.6.3 WeG frequently refers to engagement with non user-led disability charities.
- 4.6.4 DHSC in particular prioritises engagement with charities and ignores requests to meet with DDPOs.<sup>267</sup> DDP who have experience of living in the community and speaking up on disability justice issues are dying out, while the younger generation are denied life chances and spoken *about* and *for*.<sup>268</sup>
- 4.6.5 WeG disability “Regional Stakeholder Networks” are not independent of government. Chairs are public appointments and potential conflicts of interest include: “membership of organisations whose aims might be perceived to be in conflict with those of the Cabinet Office the DWP”.<sup>269</sup>
- 4.6.6 Although from May 2022 DDPOs have had regular meetings with the Minister for DDP, key policy proposals on welfare reform, employment

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<sup>267</sup> [Inclusion London \(2022\). Westminster Government Shadow Report. \[online\]](#) pp.130-133

<sup>268</sup> Through for example rising special school provision and growing barriers to independent living.

<sup>269</sup> [Disability Unit \(2023\). Overview and information pack. \[online\]](#) 17 March.

support or social care have not been shared<sup>270</sup> or substantively discussed.

4.6.7 DDPOs views on new dangerous proposals in the disability and health white paper have not been listened to. WeG is now inviting participation in drafting the legislation required to enact those plans without room to alter them.

4.6.8 There is no support for DDPOs through the National Disability Strategy.<sup>271</sup>

4.6.9 DDP are concerned that the EHRC is unable to adequately fulfil its role as a National Human Rights Institution for England and Wales and one that is sufficiently independent from WeG.<sup>272</sup>

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<sup>270</sup> The disability and health White Paper was an agenda item at the meeting between DDPO Forum and the Minister for DDP on the 20.06.23; DDPOs just shared information on what they want to see, no information was shared from the government.

<sup>271</sup> In 2021 WeG awarded a large sum of money to the national disability charities as grant funding. This was not offered through due procurement processes and DDPOs were not given an opportunity to bid. [DHSC \(2021\). Disability charities benefit from £2.4 million fund. Gov.uk, \[online\] 30 March.](#)

<sup>272</sup> Having experienced budget cuts down from £62m in 2010 to £17.4m by 2020. The EHRC Disability Advisory Committee (DAC) was scrapped without an equality impact assessment or consultation with DDPOs. EHRC has consistently declined to carry out an independent inquiry into benefit deaths. While commissioning DDPOs to write the 2022 CRDP shadow report, EHRC officials would not mention or discuss the special inquiry, presumably due to its political sensitivities. DDP who are transgender have raised concerns about the EHRC's independence and their position on trans rights issues. These issues have prompted an outcry from LGBTQ+ organisations seeking to have the EHRC "A rating" removed. Brooks, L. (2022). [LGBT+ groups call for EHRC to lose international status over trans stance. The Guardian, \[online\] 11 February.](#) Siddique, H. (2021). [EHRC undermined by pressure to support No 10 agenda, says ex-chair. The Guardian, \[online\] 18 January.](#)

- 4.6.10 Anti-protest legislation forced through by the Home Secretary criminalises peaceful protest and will limit the ability of DDP to get our voices heard and to raise public awareness of issues affecting DDP.<sup>273</sup>
- 4.6.11 DDP are being disenfranchised by a new voter ID requirement.<sup>274</sup>
- 4.6.12 At LA level other DDPOs are frightened of speaking out for fear of losing funding and being unable to run user-led services for the benefit of local DDP.<sup>275</sup>

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<sup>273</sup> Changes pushed through by the Home Secretary using a constitutional trick that's never been used before mean police can now restrict or stop a protest if they believe it could cause "more than minor disruption to the life of the community". They have the power to arrest anyone taking part in a protest, or even anyone encouraging others to take part. [Ramsey, R. \(2023\). How police in England can now stop basically any protest. \*OpenDemocracy\*, \[online\] 15 June.](#)

<sup>274</sup> Voter ID, which needed to be used for the first time in elections this Spring. Around 14,000 people were turned away at the Spring elections because they lacked ID, although according to the Electoral Commission, the true figure is likely to be much higher. The survey evidence suggests that disabled and unemployed people were more likely than other groups to give a reason related to ID for not voting. [Pring, J. \(2023\). Survey suggests tens of thousands of DDP failed to vote due to ID rules. \*Disability News Service\*, \[online\] 29 June](#)

<sup>275</sup> Such fears led one DDPO to submit evidence to us for this report anonymously. Lack of funding has forced many organisations to close. In 2019 the National Service User Network reported the closure of 200 user led organisations over the past two years. The consequence is that increasingly we are returning to a situation where DDP are spoken about and for and non user-led charities dominate the disability sector reinforcing the charity model of disability. [Pring, J. \(2019\). Council accused of 'settling scores' after cutting funding from DDPO that criticised it. \*Disability News Service\*, \[online\] 11 April ; Pring, J. \(2019\). User-led sector 'faces threat of extinction'. \*Disability News Service\*, \[online\] 14 February](#)

## Engagement, monitoring and data – Northern Ireland

- 4.6.13 To date in NI there is no formal monitoring of the UNCRPD undertaken by Government Departments. The absence of an Executive continues to hinder this work.
- 4.6.14 There is no official collection of appropriate data related to the lived experience of DDP or the impact of changes in legislation with respect to disability in NI.<sup>276</sup>
- 4.6.15 The decision to end the Core Grant of Disability Action by the Department of Health will have severe impacts on DDP.
- 4.6.16 Through our core grant funded services Disability Action have delivered information and advice to 45,000 DDP.
- 4.6.17 The services that we provide are protective and preventative and we deliver them on behalf of the Department of Health at a cost to the Department of approx. £2.88 per person.
- 4.6.18 In 2022/23 we involved more than 1400 DDP in decision making. By supporting people through our information, advice and advocacy work we reduce health inequalities and ensure that DDP can enjoy independent living.
- 4.6.19 The removal of the core grant from Disability Action will negatively impact on the effective implementation of Ministerial directives and policies on a cross Departmental basis. In addition, the removal of the core grant from Disability Action effectively removes our ability to engage in UN accredited human rights work.

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<sup>276</sup> DFC (2020) [Disability Expert Panel Report and Recommendations](#) p.25 (accessed 15 December 2021)

## Engagement, monitoring and data – Scotland

- 4.6.20 The Scottish Government must do more to monitor outcomes for DDP and fill data gaps in a consistent way. To fully implement the recommendations of the 2016 Inquiry, the Scottish Government first needs to identify the best way to measure the cumulative impact of laws, policies and practices including through experiential research, and the data gaps that exist and how to address them.
- 4.6.21 Intersectional discrimination is a major issue and its impact is not always immediately apparent to policy and decision-makers. There is a widespread lack of focus and understanding of intersectional barriers and this is underpinned by a clear lack of intersectional data in Scotland which makes it difficult to set baselines and targets and to monitor outcomes. This includes DDP generally, but also applies to specific impairment types, in particular for people with a learning disability.<sup>277</sup>

## Engagement, monitoring and data – Wales

- 4.6.22 We are concerned about the lack of data on DDP living in Wales. We are particularly concerned about the lack of data on DDP with multiple marginalized identities, such as racialised DDP and LGBTQA+ DDP.<sup>278</sup> Disability Wales is pleased to see data on the number of DDP with other protected characteristics in England and Wales published, but

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<sup>277</sup> [The challenges of estimating Scotland's learning disabled population and why it matters | FAI \(fraserofallander.org\)](#)

<sup>278</sup> Dr Wahida Shah Kent, University of South Wales Unit for Development in Intellectual and Developmental Disabilities", 21<sup>st</sup> October 2021, <https://udid.research.southwales.ac.uk/news/black-and-minority-ethnic-groups-learning-disability-and-need-ethnicity-data/>

we need further data, not just on the number of DDP with other protected characteristics, but their experiences.<sup>279</sup>

## 4.7 Housing

### Housing – England (WeG)

- 4.7.1 DDP are further segregated from society by a lack of suitable housing. There is significant unmet housing need.
- 4.7.2 In 2018 the EHRC published a report on housing and DDP called “Britain’s housing crisis”, covering England, Scotland and Wales.<sup>280</sup> It cited WeG data of 365,000 DDP living in unsuitable properties in England while the average waiting time for an accessible property was 25 months<sup>281</sup>. The figure is likely to be higher now. Unsuitable conditions include DDP unable to bathe or leave their homes.<sup>282</sup>

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<sup>279</sup> Census 2021, Office of National Statistics, “Protected characteristics by disability status, England and Wales: Census 2021”, 17<sup>th</sup> May 2023, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/protectedcharacteristicsbydisabilitystatusenglandandwalescensus2021/2023-05-17#ethnic-group>

<sup>280</sup> EHRC (2018). *Housing and DDP: Britain’s Housing Crisis* [online] p.21

<sup>281</sup> EHRC (2018), *Housing and DDP*, [online]. Available at: <https://www.equalityhumanrights.com/en/housing-and-disabled-people-britain%E2%80%99s-hidden-crisis> Accessed on: 15.03.22

<sup>282</sup> See above. Also case studies in Ryan, F. (2019) *Crippled: Austerity and the Demonization of DDP*. London: Verso, p.107.

- 4.7.3 WeG policy does not adequately address the lack of suitable housing.<sup>283</sup> DDP are disproportionately reliant on social housing.<sup>284</sup> Private renting can be unsuitable for a number of reasons including discrimination by landlords, inability to make up the shortfall between housing benefit payments and market rents, and the need for security of tenure.
- 4.7.4 The Equality Act 2010 does not provide sufficient safeguards against housing discrimination. According to the housing charity Shelter, tenants who are disabled or from racialised minorities are disproportionately likely to face discrimination looking for a home, and to end up inhabiting shoddy, unsafe and unsuitable accommodation.<sup>285</sup>
- 4.7.5 The NDS included proposals to encourage home ownership among DDP and invest in the building of more segregated “supported housing”<sup>286</sup> with nothing to address the substantive issue of accessible social housing stock.
- 4.7.6 Problems with housing are compounded by LA and Housing Association failures to carry out repairs and maintenance.<sup>287</sup>

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<sup>283</sup> [MHCLG \(2021\). \*The charter for social housing residents: social housing white paper\*. \[online\].; Pring, J. \(2019\). \*Government faces legal action threat over accessible housing failure\*. \*Disability News Service\*, 19 September.](#)

<sup>284</sup> According to figures from 2019, one-quarter (24.7%) of DDP rented social housing, compared with just 8.2% of non-DDP. [ONS \(2019\). \*Disability and housing, UK: 2019\*. \[online\] 2 December.](#)

<sup>285</sup> [Butler, P. \(20\). \*Black, Asian and disabled tenants ‘more likely to face housing discrimination’\*. \*The Guardian\*, \[online\] 26 May.](#)

<sup>286</sup> NDS 2021, pp.38-39.

<sup>287</sup> *Surviving Squalor: Britain's Housing Shame* (2021). [TV programme] ITV, 12 September: 22.15.

Conditions such as water penetration, damp, mould and pest infestations exacerbate existing impairments while creating others.

- 4.7.7 Six years ago, 72 people were killed by a fire that broke out in the Grenfell tower in London.<sup>288</sup> Among them were disabled residents, who due to the chronic shortage of accessible housing, had been housed by their local LA on upper floors with no way to escape in case of fire.
- 4.7.8 41% of people who died were Disabled and 85% were Black people and from racialised minorities, raising issues of institutional racism as well as disablism.<sup>289</sup>
- 4.7.9 The EHRC found that DDP who died in Grenfell Tower had their human rights breached by public bodies that failed to plan how they would evacuate their homes in the event of a fire.<sup>290</sup>
- 4.7.10 Today DDP are still fighting for protections from fire risks if placed in high-rise housing.<sup>291</sup> WeG rejected the Grenfell Tower Inquiry's recommendation that owners and managers of high-rise residential buildings should prepare a personal emergency evacuation plan (PEEP) for all residents who might find it difficult to "self-evacuate".
- 4.7.11 The high court has now found that fire minister Lord Greenhalgh had decided by September 2021 "not to implement the PEEPs

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[Hewitt, D. \(2021\). Britain's Housing Shame: A story of shocking conditions and tenants' despair at a lack of action. \*itvNEWS\*, \[online\] 12 September.](#)

<sup>288</sup> [Disability Rights UK \(2021\). Grenfell Tower fire is 'a landmark act of discrimination against disabled and vulnerable people'. \*disabilityrightsuk.org\*, \[online\] 22 April.](#)

<sup>289</sup> Ibid.

<sup>290</sup> [Pring, J. \(2019\). Disabled Grenfell residents were repeatedly failed in years before fire, inquiry finds. \*Disability News Service\*, \[online\] 31 October.](#)

<sup>291</sup> [Pring, J. \(2023\). Minister made 'political' decision to rule out safe evacuation for DDP. \*Disability News Service\*, \[online\] 20 July.](#)

recommendations”, but also concluded that it would be too dangerous politically to make that decision public.

### **Housing – Northern Ireland**

- 4.7.12 Research undertaken by Disability Action on behalf of the Equality Commission demonstrates that 8 out of 10 DDP believe housing is inaccessible to them. NI is experiencing a housing emergency- which is having a severe impact on DDP. 52% of the social housing waiting list are older people, DDP and people experiencing mental health challenges.
- 4.7.13 The most recent published data from the Department for Communities (DfC) demonstrates that there are only 1,111 accessible social homes in the region, yet according to the most recent census<sup>1</sup> in 4 people in NI are DDP. There is a significant undersupply of accessible housing in the region. DDP are trapped in unsuitable housing due to this housing shortage.
- 4.7.14 DDP are trapped in unsafe and undignified housing. Through our case work we know that DDP have faced challenges in having their doors widened and ramps fitted.
- 4.7.15 We have worked with DDP who have been unable to access dignified toileting in their home because they cannot access the stairs to use the toilet. The conditions in which they are living are devastating leading to declining physical and mental health.
- 4.7.16 Living in inappropriate housing has negative impacts on quality of life, and physical and mental health.
- 4.7.17 Adaptation grants are available, but they are means tested and the process for applying is complicated- it is our position that resources for adaptation should be available based on need and not income. If a family receives child benefit for the young person- then the test of

resources is not applied. Grants are only paid once the work is completed which presents a significant barrier top draw done.

- 4.7.18 Disabled residents in NI, in the private housing sector, whose adaptations were completed in 2020/21, and the first seven months of 2021/22 (up to 31 October 2021), waited more than three years on average for them to be finished.
- 4.7.19 Disabled residents in the private housing sector have waited between nine and 20 months on average for home adaptations to be completed once they'd received an 'approval of application' from the Housing Executive in 2020/21.
- 4.7.20 The current political crisis has resulted in a series a lack of accountability which coupled with a public finance crisis has resulted in a series of decisions which adversely impact upon DDP.
- 4.7.21 With respect to housing, it has been proposed that the NI Housing Executive Budget will be reduced. Reductions to the NIHE budget by DfC will lead to longer delays in housing adaptations, and increased risk of homelessness all of which disproportionately impact upon DDP.
- 4.7.22 There is a significant deficit in the provision of accessible social homes. The reduction in building will further reduce opportunities for DDP to access an accessible home. The lack of access to housing, housing adaptations and housing support will lead to the re-institutionalisation of DDP which will increase spending within the Department of Health.
- 4.7.23 The proposed decision by DfC to reduce the NIHE budget<sup>292</sup> requires a cross Departmental cumulative assessment.

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<sup>292</sup> <https://www.communities-ni.gov.uk/sites/default/files/consultations/communities/dfc-budget-2023-24-egia.pdf> p.21

## Housing – Scotland

- 4.7.24 DDP are still living in inaccessible housing.<sup>293</sup> In 2019, 14% of households with a disabled member said their house was not fully accessible. For people living in local authority housing, this was a quarter (26%).<sup>294</sup>
- 4.7.25 There is a chronic shortage of accessible and adapted housing.<sup>295</sup> Research showed that 17,226 wheelchair users were living in unsuitable homes and this unmet need is set to increase by 80% by 2024, based on current health trends which project a sharp rise in the number of wheelchair users.<sup>296</sup>

## Housing – Wales

- 4.7.26 A lack of appropriate accommodation locally, some DDP have reported having to move far from support networks or feeling forced into certain living situations due to the availability of accommodation.
- 4.7.27 One disabled person reported that they experienced an attempt to force them to move into residential accommodation 50 miles away from their friends, they were told that a court order would be made to force them to accept accommodation.<sup>297</sup>

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<sup>293</sup> Age Scotland (2020), [National Housing Survey – Report](#)

<sup>294</sup> Scottish Government (2020), [Scottish Household Survey 2019](#)

<sup>295</sup> Equality and Human Rights Commission (2018), [Housing and DDP: Scotland's hidden crisis](#)

<sup>296</sup> Horizon Housing et al (2018), [Still minding the step? A new estimation of the housing needs of wheelchair users in Scotland](#)

<sup>297</sup> “[I] 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.”

4.7.28 Access to appropriate housing is a key concern for many DDP in Wales. Housing organisations in Wales have raised concerns about insufficient quality social housing being built in Wales,<sup>298 299 300</sup> 67% of respondents to a survey conducted by the Bevan Foundation supported building more social housing.<sup>301</sup>

## 4.8 Independent Living

### Independent living – England (WeG)

#### Education

4.8.1 There is severe and deliberate retrogression of DDP’s right to inclusive education in line with WeG’s continuing reservation and interpretative declaration on this article.

4.8.2 Placements in segregated “special schools” compared to mainstream education have increased steadily since 1999. Between 1999 and 2021, the percentage of children in England with an EHCP attending “mainstream” education fell from 64.6% to 50.4%, while those

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<sup>298</sup> Simon Hoffman, Tai Pawb, (June 2019), The Chartered Institute of Housing Cymru and Shelter Cymru, The Right to Adequate Housing in Wales: Feasibility Report, <https://www.taipawb.org/wp-content/uploads/2019/06/RightToHousing-Full-ENG.pdf>

<sup>299</sup> Mike Hedges MS, Bevan Foundation, “Build Build Build”, (February 2022), <https://www.bevanfoundation.org/views/build-build-build/>

<sup>300</sup> Rob Simkins, Shelter Cymru, (December 2020), “Politicians Have Listened to Our Social Housing Campaign. Now its Time for them to Take Action”, <https://sheltercymru.org.uk/politicians-have-listened-to-our-social-housing-campaign-now-its-time-for-them-to-take-action/>

<sup>301</sup> Bevan Foundation, A Snapshot of Poverty in Winter 2021, (December 2021), <https://www.bevanfoundation.org/wp-content/uploads/2021/12/A-snapshot-of-poverty-in-winter-2021-.pdf>

attending “special schools” and other forms of segregated education rose from 35.4% to 49.6%.

- 4.8.3 In 2021 there was an additional 11,655 pupils without an EHCP educated in segregated settings.
- 4.8.4 WeG has invested in “59 new free special schools for children with complex SEND” and “a further 75 are in the pipeline”<sup>302</sup>. The Chancellor’s Autumn 2021 budget included a pledge to invest £2.6 billion for Disabled CYP in England.
- 4.8.5 Previous SEND capital grants went either to fund new special school buildings or segregated units either within or acting as satellite provision for mainstream schools. This new money could expand special school placements by 30,000.<sup>303</sup>
- 4.8.6 Declining support in mainstream schools means families too often have no other choice but to opt for special education. There is also an increase in disabled pupils being educated outside of school.<sup>304</sup>
- 4.8.7 The high court found that SEND cuts proposed by Bristol LA were unlawful<sup>305</sup> but the SEND crisis is ongoing<sup>306</sup>. In 2020, SEND tribunal

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<sup>302</sup> [Disability Unit \(2021\). National Disability Strategy. \[online\]](#), p.66

<sup>303</sup> [Keer, M. \(2021\). New Budget funds for SEND capital spending. But how did LAs spend previous cash? We checked.... Special Needs Jungle, \[online\] 28 October.](#)

<sup>304</sup> [Alliance for Inclusive Education \(2022\). Education professionals and the ‘institutional lie’ about cuts. Inclusion Now 64, \[online\] 22 December](#)

<sup>305</sup> [Keer, M. \(2018\). Legal victory for Bristol parents against SEND cuts – what does it mean for other areas? Special Needs Jungle, \[online\] 6 August.](#)

<sup>306</sup> [Smith, J. \(2021\). Bristol Send Crisis Shows Little Signs of Improvement for Families. Chopsy Bristol, \[online\] 6 October.](#)

panels upheld only 5% of LA decisions.<sup>307</sup> Families are having to go through expensive, time-consuming and stressful tribunals to get legal rights enforced.

- 4.8.8 Disabled pupils are between 2.5 and 5 times more likely to receive permanent exclusions than non-disabled pupils.<sup>308</sup>
- 4.8.9 Intersectional injustices between disability and other protected characteristic such as race, gender, age, etc and social issues continue to present significant barriers and discrimination for DDP within the education system.
- 4.8.10 Factors such as poverty and unsafe family environments all subject disabled children and their families to higher rates of exclusion or home schooling.<sup>309</sup> These additional injustices are also amplified for marginalised communities, for example, people in Black and Global Majority families are between two and three times to be living in poverty than people in White families.<sup>310</sup>
- 4.8.11 According to official figures on permanent exclusions for 2019/2020, a Black disabled boy on Free School Meals (FSM) and with an EHCP has a

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<sup>307</sup> Only 193 of 3,770 hearings in favour of the LA decision – the worst success rate on record. [Keer, M. \(2020\). 95% of decisions in favour of parents, but nobody wins at the SEND Tribunal. \*Special Needs Jungle\*, \[online\] 11 December.](#)

<sup>308</sup> Disabled pupils without an EHCP are five times more likely to receive a permanent exclusion than non-disabled pupils. For disabled pupils with an EHCP the figure is 2.5 times more likely. [Department for Education \(2021\). \*Permanent exclusions and suspensions in England: 2019 to 2020\*. \[online\] 29 July.](#)

<sup>309</sup> [HM Government \(2020\). \*Timpson Review of School Exclusion. CP92\*, \[online\] May, p.34.](#)

<sup>310</sup> [Social Metrics Commission \(2020\). \*Measuring Poverty 2020\*. \[online\].](#)

74.75% chance of permanent exclusion; for a Black Disabled Caribbean boy on FSM without an EHCP his chance is 149.5%<sup>311</sup>.

- 4.8.12 Contact a Family reported that families are missing out £600 per year on FSM for reasons such as Education Other than School, pupils educated outside of school, and long term illness.<sup>312</sup>
- 4.8.13 Disabled Pupils who are Gypsy or Roma have the highest rate of exclusions being more than three times likely as a White British child to be excluded.<sup>313</sup>
- 4.8.14 Life outcomes for excluded pupils are poor. Pupils officially excluded from school at age 12 are four times more likely to be in prison by age 24<sup>314</sup>. David Lammy MP is quoted as saying, “The relationship between pupil referral units [a type of alternative provision maintained by the local authority] and the criminal justice system has become symbiotic, and the rise of exclusions is creating a pipeline of young people into our prison system.”<sup>315</sup>
- 4.8.15 Students who are Deaf/Disabled face entrenched barriers to higher education. A number of universities have faced criticism for disability discrimination over recent years.<sup>316</sup>

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<sup>311</sup> [Statistics derived from analysis of: Department for Education \(2021\). \*Permanent exclusions and suspensions in England: 2019 to 2020\*. \[online\] 29 July.](#)

<sup>312</sup> [Contact a Family \(n.d.\) Free school meals for disabled children. \*contact.org.uk\*, \[online\]](#)

<sup>313</sup> Ibid.

<sup>314</sup> [The Edinburgh Study of Youth Transitions and Crime \(2016\). Study links school exclusion to prison. \[press release\] 6 April.](#)

<sup>315</sup> [Weale, S. \(2017\). School exclusions data in England only 'the tip of the iceberg'. \*The Guardian\*, \[online\] 17 October](#)

<sup>316</sup> [Pring, J. \(2020\). Disabled students 'face appalling barriers' at latest university to face discrimination claims. \*Disability News Service\*, \[online\] 13 August](#)

- 4.8.16 A 2020 report concluded that disabled students are often forced to interrupt their studies because of the “financial burden, a lack of support, and struggling to fully access their teaching and learning”, while the complaints process creates further barriers.<sup>317</sup> The report called for reform of the Disabled Students Allowance (DSA) system.
- 4.8.17 The Government published this year March 2023 Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan setting out their plans. They did not define inclusive education. Instead, they will:

“Invest £2.6 billion between 2022 and 2025 to fund new places and improve existing provision for children and young people with SEND or who require alternative provision.” and for 2023: “Announce the successful schools which will be opened as part of the new special and alternative provision free schools.”<sup>318</sup>

### **Mental Health**

- 4.8.18 WeG continues to employ legislation entrenched in a medical not a human rights approach, which authorises deprivations of liberty based on psychosocial and intellectual disabilities.
- 4.8.19 Following a review of the Mental Health Act 1983,<sup>319</sup> WeG has issued a draft Mental Health Bill (2022) as a basis for change. However, the

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<sup>317</sup> [Higher Education Commission \(2020\). \*Arriving At Thriving: Learning from disabled students to ensure access for all.\* \[online\] 6 October](#) ; [Pring, J. \(2020\). Disabled students call for strict new rules for universities that fail on access. \*Disability News Service\*, \[online\] 5 November](#)

<sup>318</sup> [ALLFIE \(2023\). \*Special Educational Needs and Disabilities \(SEND\) and Alternative Provision \(AP\) Improvement Plan: Headlines. Briefing\*, \[online\] 2 March](#)

<sup>319</sup> [Wessely, S. \(2018\) \*Modernising the Mental Health Act: increasing choice, reducing compulsion. Final report of the independent review of the Mental Health Act 1983\* \[online\], 6 December](#)

planned changes remain non-compliant with the CRDP.<sup>320</sup> Key examples of breaches include:

- The stated intention to reduce, but not to abolish substitute decision-making, detention in psychiatric institutions, involuntary treatment and the use of community treatment orders (CTOs) and to maintain provision for guardianship
- The continuing employment of a mental capacity, not a legal capacity base
- An extension of the role of advocates and a new nominated person role for patients which rest on the assumption that compulsory powers should continue
- The lack of focus on intersectional discrimination
- The proposal to relate fewer of the planned changes to detained patients in the criminal justice system – and the new power of ‘supervised discharge’.<sup>321</sup>

4.8.20 A Parliamentary Joint Committee has recommended further changes<sup>322</sup> related to the points above and to further increases in community services, especially for people with ‘learning disabilities’ and ‘autism’; adequate resourcing for planned changes; comprehensive training for the workforce; improved data collection; clear action programmes and monitoring processes. However, apart

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<sup>320</sup> They are in breach of Articles 19 and closely linked Articles such as 12 and 14, Articles 5 and 6, General Comment 5 (Sections 15a, 15d, 20, 27, 47, 48, 81, 83 and 98a), General Comment 1, CRPD Guidance on Article 14, and the CRDP deinstitutionalisation guidelines.

<sup>321</sup> This equates to a deprivation of liberty in the community for those whom clinicians judge could be released from hospitals, but remain a risk.

<sup>322</sup> [Parliament. House of Commons. House of Lords. Joint Committee on the Draft Mental Health Bill, \(2023\) Draft Mental Health Bill 2022. Report of Session 2022-23 \[online\], 11 January.](#)

from a call to abolish CTOs, the Committee’s proposals remain non-compliant with the CRDP.

- 4.8.21 A WeG response to the Committee’s recommendations has been postponed and will not now occur before the autumn.
- 4.8.22 The Mental Capacity (Amendment) Act 2019<sup>323</sup>, which amends the Mental Capacity Act 2005<sup>324</sup>, also remains non-compliant with the CRDP. Its Liberty Protection Safeguards (due in 2024 now) continue to draw on mental capacity concepts, instead of acknowledging legal capacity, and to allow disability-based deprivations of liberty.
- 4.8.23 In addition, in contrast to the CRDP deinstitutionalisation guidelines<sup>325</sup>, none of the measures outlined above address the need to make reparation for the violation of human rights intrinsic to disability-based deprivations of liberty.
- 4.8.24 In December 2022, NHS leaders warned that NHS mental health services are being left to fail, with patients and service users routinely struggling to access both urgent and routine care. They said that staff and services are stretched to capacity with many now under crippling and unsustainable pressure.<sup>326</sup>
- 4.8.25 Pre-pandemic both child and adult mental health services were over-stretched and facing escalating demand set against funding cuts. Professionals described Child and Mental Health Services (CAMHS) as

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<sup>323</sup> [Mental Capacity \(Amendment\) Act 2019, c.18 \[online\], 16 May](#) This amends the Mental Capacity Act 2005 which is itself non-compliant with the CRDP

<sup>324</sup> [Mental Capacity Act 2005, c.9 \[online\], 7 April](#)

<sup>325</sup> [Committee on the Rights of Persons with Disabilities, \(2022\) Guidelines on deinstitutionalisation, including in emergencies. Advance unedited version. CRPD/C/27/3/ \[online\], 9 September](#)

<sup>326</sup> [NHS Confederation, \(2022\). NHS mental health services are under unsustainable pressure health service leaders warn \[press release\] 2 December](#)

“not fit for purpose”, citing how CYP were not being seen by services until multiple suicide attempts.<sup>327</sup>

- 4.8.26 The Care Quality Commission (CQC) has warned that Issues around workforce retention and staffing shortages remain the greatest challenge for the mental health sector, that this is impacting on service provision and on the safety and wellbeing of both patients and staff.<sup>328</sup>
- 4.8.27 A cuts environment combined with the welfare reform agenda has seen provision targeted at those thought to require lower-level interventions such as Increasing Access to Psychological Therapies (IAPT), in order to support people to resume work or move from out of work benefits into employment.
- 4.8.28 Between 2015 and 2020 there were 56 mental health-related deaths in England and Wales where coroners identified a lack of staffing or service provision as a “matter of concern”, meaning they believed “there is a risk that future deaths could occur unless action is taken”,<sup>329</sup> and particular shortfalls for people in greatest need.<sup>330</sup>
- 4.8.29 However, whilst resource shortfalls are undoubtedly an issue, the views cited above fail to address the fundamental problem: even if funding were adequate, a mental health system based on human rights violations, and on a dominant medical model instead of the

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<sup>327</sup> [BBC News \(2018\). Child mental health: Camhs 'not fit for purpose'. BBC.co.uk, \[online\] 24 September](#)

<sup>328</sup> [Care Quality Commission \[CQC\], \(2022\). Monitoring the Mental Health Act in 2021 to 2022 \[online\], 1 December](#)

<sup>329</sup> [Jayanetti, C. \(2021\). Coroners warned of mental health care failings in dozens of inquests. The Guardian, \[online\] 5 September](#)

<sup>330</sup> [Whymark, B. \(2019\). Mentally ill father's death could spark review into psychological treatment services. Eastern Daily Press, \[online\] 30 April](#)

CRDP guidelines, will continue to fail people with psychosocial and intellectual disabilities.

### **Social Care**

- 4.8.30 Support for DDP living in the community has decreased further since 2016 through year-on-year cuts and annual savings targets within adult social care budgets.
- 4.8.31 When social care needs are not met there are extreme consequences. Research published in 2021 found that for the five years from 2010, the loss of social care funding caused 23,662 additional deaths<sup>331</sup>. It is likely this trend continued after the years under study up until the pandemic as cuts only worsened over that period.
- 4.8.32 This situation not only reflects further regression under article 19 but has now led directly to significant breaches of many other articles.<sup>332</sup>
- 4.8.33 DDP are being institutionalised in their homes through grossly inadequate support for a decent standard of living and lack of choice and control over the support they receive.<sup>333</sup>

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<sup>331</sup> [Martin, S., Longo, F., Lomas, J., Claxton, K. \(2021\). Causal impact of social care, public health and healthcare expenditure on mortality in England: cross-sectional evidence for 2013/2014. \*BMJ Open\*, vol. 11, issue 10](#)

<sup>332</sup> Including: 6 (Women), 7 (Children), 15 (Freedom from torture or cruel, inhuman or degrading treatment or punishment), 16 (Freedom from exploitation, violence and abuse), 20 (Personal mobility), 21 (Freedom of expression and opinion, and access to information), 23 (Respect for and the family), 26 (Habilitation and rehabilitation), 27 (Work and employment), 29 (Participation in political and public life), and 30 (Participation in cultural life, recreation, leisure and sport).

<sup>333</sup> General comment No. 5 (2017) on living independently and being included in the community says: “nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although

- 4.8.34 Without adequate support, many DDP are unable to participate in multiple areas of life covered by the CRDP while being at greater risk w
- 4.8.35 Cuckooing – where criminals take over someone’s home, usually that of a disabled person – is now central within criminal drug operations.<sup>334 335</sup>
- 4.8.36 There is also a significant overlap between modern slavery and disability.<sup>336 337</sup>

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institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences;” (pp. 4-5).

<sup>334</sup> [National Crime Agency \[NCA\], \(n.d.\). County Lines. nationalcrimeagency.org.uk, \[online\].](https://www.nationalcrimeagency.org.uk)

See also evidence received for our 2022 shadow report.

<sup>335</sup> In 2021, Leigh Smith was stabbed to death. His assisted living flat had been taken over by cuckooing. [Kingsley, T. \(2022\). Teenagers found guilty of ‘disturbing’ murder of vulnerable man after cuckooing his flat. Independent, \[online\] 21 January.](#)

<sup>336</sup> [Lambert, M. \(2021\). Does it matter that gangmasters are targeting people with disabilities? The Clewer Initiative, \[online\] 4 June.](#)

<sup>337</sup> People with learning difficulties and people living with mental distress are at particular risk. This is a subject that was taken up by the long-running, popular BBC radio drama *The Archers*: [BBC News \(2020\). The Archers tackles the 'hidden' connection between disability and modern slavery. bbc.co.uk, \[online\] 16 December.](#)

- 4.8.37 Children removed from their parents by the State is at the highest level on record.<sup>338 339 340 341 342</sup>
- 4.8.38 WeG’s recent announcement that it plans to set up a taskforce looking into these issues is welcome.<sup>343</sup> We would urge it to act quickly and identify concrete actions.
- 4.8.39 Community support systems are now so fragile that COVID-19 lockdowns tipped families over the edge. The deaths by neglect of two disabled young women, one in England, the other in Wales, confined in conditions unfit for animals, in separate horrific incidents led to prison sentences for their parents.<sup>344</sup> Local agency failings have been blamed with no accountability from WeG.

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<sup>338</sup> As of 31 March 2022, there were 82,170 children in care in England. [Office for National Statistics \[ONS\], \(2023\). Children looked after in England including adoptions: Reporting Year 2022. \[online\] 13 July.](#)

<sup>339</sup> The figure has been rising since 2008. [Simpson, F. \(2022\). Number of children in care at highest level on record. Cypnow.co.uk, \[online\] 17 November.](#)

<sup>340</sup> This corresponds with rising cuts to social care support. Instead of providing support to disabled parents, LAs remove their children. We received evidence on this for our shadow report consultation from [The Working Together Parents Network](#) and [Stay Safe East](#).

<sup>341</sup> Child social work teams view parental disability as a risk factor to children. [University of Bedfordshire \(2018\). Disabled parents often seen as risk to their children rather than given support, research warns. beds.ac.uk, \[online\] 21 September.](#)

<sup>342</sup> Parents with learning difficulties are 54 times more likely to have their children removed, as revealed by an investigation carried out by Channel Five news. [Nicolle, L. \(2023\). Children of parents with a learning disability 54 times more likely to be taken into care. learning disability today, \[online\] 25 January.](#)

<sup>343</sup> [Disability Unit, Equality Hub, and Pursglove, T. \(2023\). Disability Action Plan. \[online\] CP 873 p.60](#)

<sup>344</sup> Debbie Leitch (England) and Kaylea Titfordd (Wales). See Appendix 1 for their tragic stories. [Clifford, A. and Scheer, V. \(2023\). Woman, 24, starved to death by her evil Leeds mum](#)

- 4.8.40 Without appropriate community-based support, governments have struggled to de-institutionalise services for people with learning difficulties and autism.
- 4.8.41 Institutional support places DDP at risk of abuse and neglect within closed cultures.<sup>345</sup>
- 4.8.42 WeG Health and Social Care Act 2022 focuses on social care support as an older person's issue and there was a complete absence of engagement with DDPOs.
- 4.8.43 When DDPOs wrote to the Secretary of State for Health and Social Care asking to meet he was too busy.<sup>346</sup> There was not one social care user among the 43 "leaders and experts" he assembled for a health and social care reform summit.<sup>347</sup> The Care Services Minister admitted she is unaware of the views of DDPOs on WeG's social care reforms.<sup>348</sup>
- 4.8.44 Of the £5.4bn of new funding for social care from 2022-2025, only £1.7bn will go towards the wider system; the rest will be spent on

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[was failed by safeguarding agencies. LeedsLive, \[online\] 30 April.](#) ; [BBC News \(2023\). Kaylea Titford: Neglected teen left to die alone at home by parents. bbc.co.uk, \[online\] 2 March](#)

<sup>345</sup> Abuse scandals at a number of institutions have resulted in largescale criminal proceedings such as the undercover filming of abuse and mistreatment of residents at Whorlton Hall, a private institution in England. Nine former staff members are due to face a five week trial in 2023. [Triggle, N. \(2019\). Whorlton Hall: Hospital 'abused' vulnerable adults. BBC News, \[online\] 22 May.](#) [Huntley, D. \(2021\). Nine former care workers to face trial in 2023 after denying patient abuse allegations. Chronicle Live, \[online\] 7 December.](#)

<sup>346</sup> [Inclusion London \(2022\). Westminster government shadow report. \[online\],](#) appendix 8

<sup>347</sup> [Pring, J. \(2021\). Minister invited 44 'leaders' to care summit, but not one DDP's organisation. Disability News Service, \[online\] 14 October](#)

<sup>348</sup> [Pring, J. \(2018\). Care minister admits ignoring views of DDP on government's reforms. Disability News Service, \[online\] 7 October](#) ; [Pring, J. \(2021\). Government 'ignored DDPOs' in drawing up social care white paper. Disability News Service, \[online\] 9 December](#)

implementing a new social care cap<sup>349</sup>. The legislation has minimal relevance to DDP of working age who are far less likely to have acquire assets.<sup>350</sup>

- 4.8.45 The new funding is being raised via a Health and Social Levy raised through National Insurance contributions and will slightly increase poverty rates, from 16.2% to 16.3%.<sup>351</sup>
- 4.8.46 The British Medical Association estimates that £7.9bn a year in social care funding on top of the Health and Social Care Levy is needed by 2024/25.<sup>352</sup>
- 4.8.47 Government funding for local authorities was cut by 55% between 2010/11 and 2019/20, resulting in a 29% real-terms reduction in local authority spending power. Local authority spending on social care has fallen as a result.<sup>353</sup>
- 4.8.48 As at the end of April 2022, there were 542,000 people waiting for social care support assessments, care packages, direct payments or reviews with social care waiting lists having grown by 37% in less than six months. In September 2022, the Care and Support Alliance

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<sup>349</sup> [Foster, D. \(2021\). \*Proposed reforms to adult social care \(including cap on care costs\)\*. Research Briefing, \[online\] 11 February.](#)

<sup>350</sup> The cap limits the amount that any individual will need to pay towards the costs of social care within their lifetime. The cap is contrary to the system originally legislated for, but never implemented, in the Care Act 2014. It will mean people with lower levels of assets will need to spend the same as wealthier people before reaching the cap.

<sup>351</sup> [Institute for Social and Economic Research \(2021\). \*How will the new Health and Social Care Levy impact on household incomes\*. University of Essex, \[online\] 20 September.](#)

<sup>352</sup> [British Medical Association \[BMA\], \(2022\). \*Who Cares? The need for real reform for social care in England\* \[online\], June](#)

<sup>353</sup> One in four had been waiting longer than six months for their assessment. [National Audit Office \[NAO\], \(2021\). \*The adult social care market in England\* \[online\], March](#)

estimated that 2.6 million people aged 50 and above were living with some form of unmet need for care in England.<sup>354</sup>

- 4.8.49 Social care administration in England is divided between 152 local authorities (LAs).<sup>355</sup>
- 4.8.50 LAs have a legal duty to set a balanced budget each year. With cuts to funding from central government alongside rising demand, tightening eligibility and savings target within adult social care have become the major focus.
- 4.8.51 The percentage of cases upheld by the Local Government and Social Care Ombudsman (LGSCO) has shown a relentless rise over the last decade. The faults the Ombudsman finds in its investigations are often not due to one-off staff errors, but are increasingly caused by the measures employed by councils and care providers to mitigate the squeeze on their resources.<sup>356</sup>
- 4.8.52 The sustainability of the social care support system is in question. One in two councils has had to respond to a care home closure or bankruptcy over the past six months.<sup>357</sup>

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<sup>354</sup> [Jayanetti, C. \(2022\). New analysis finds 2.6m people over 50 have unmet care needs. \*Social Care Today\*, \[online\] 7 September](#)

<sup>355</sup> Each time a new national initiative or guidance is introduced, each LA must set up its own project team and create its own policies and procedures for implementation.

<sup>356</sup> Michael King, the LGSCO has described “a system with a growing disconnect between the care to which people are entitled, and the ability of councils to meet those needs.” Key features of cases investigated in 2021/22 were care assessments, care planning and charging for care. King cited councils failing to provide care, or limiting it, and justifying this because of the cost as a common theme. [LGSCO \(2022\). \*Complaints about English social care increasingly due to funding constraints\*. \[press release\] 12 October](#)

<sup>357</sup> [ADASS, \(2021\). \*Snap Survey reveals a rapidly deteriorating picture of Social Care Services\*. \*Press Release\*, 29 November](#)

- 4.8.53 Support for DDP to manage Direct Payments and directly employ PAs has been cut to the bone.<sup>358</sup> This means they have no support to make sure they meet their obligations under employment law.
- 4.8.54 Social care charging is having an increasingly detrimental impact on the incomes of DDP, forcing many to go without support while others are trapped in debt. Only one LA in England does not charge for social care support.
- 4.8.55 According to charging rules, LAs need to leave DDP with a set minimum income. The minimum income level is set by the Treasury/DHSC. It stayed the same for five years during the benefit freeze and beyond. Only this year (2023) did it rise to account for inflation.
- 4.8.56 Social care charges have risen considerably over recent years. Research by the BBC in 2021 found some disabled adults were paying thousands of pounds extra a year, with six councils doubling the amount of money collected in charges. In half of 83 areas that responded to a BBC request, bills across all users have risen at least 10% over two years.<sup>359</sup>
- 4.8.57 Increasing numbers of DDP in England owe debts to their LAs for social care charges they cannot afford. In 2021/22 more than 60,000 disabled adults had debt collection procedures started against them by

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<sup>358</sup> We received a number of submissions on this for our 2022 shadow report

<sup>359</sup> [BBC News \(2021\). Social care charges: Disabled and vulnerable adults hit by steep rises. \*bbc.co.uk\*, \[online\] 24 August.](https://www.bbc.com/news/health-57811111)

their LA.<sup>360</sup> A previous investigation in 2018 found over 166,000 people in arrears on their social care payments.<sup>361</sup>

- 4.8.58 People who are too disabled to work are hit harder by the cost of social care support than those in paid employment since the financial assessment for charging does not take into account earned income. Income from disability benefits is taken into account and clawed back through charging.
- 4.8.59 In 2020, the high court ruled that Norfolk County Council’s new policy discriminated against “severely disabled” people under the European Convention on Human Rights because the council would be charging those with the highest support needs proportionately more than those with lower support needs.<sup>362</sup>

### **Independent Living – Northern Ireland**

- 4.8.60 To date within NI there has been no statutory definition of Independent Living or a coherent strategy through which to promote Independent Living<sup>363</sup>. The reform of Adult Social Care has been promised since 2016. Proposals were consulted upon in July 2022.

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<sup>360</sup> This is data from just 79 out of 152 LAs in England. The other 83 LAs did not respond to the Freedom of Information request. [BBC News \(2023\). Social care costs see thousands chased for debt. \*bbc.co.uk\*, \[online\] 22 February.](#)

<sup>361</sup> More than 78,000 of these had debt management procedures started against them for non-payment. The true figure is likely to be higher as not all LAs responded and there is no central monitoring by WeG. [GMB Union \(2018\). At least 166,000 trapped in social care debt. \[press release\] 4 June.](#)

<sup>362</sup> [SH, R \(On the Application Of\) v Norfolk County Council & Anor \(Rev 1\) \[2020\] EWHC 3436 \(Admin\) \(18 December 2020\)](#)

<sup>363</sup> DfC (2020): [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#), p.36

There has been no progress since due to the absence of an Assembly and Executive.

- 4.8.61 The absence of an integrated strategy for Independent Living combined with little or no co-ordination between services relating to education, childcare, transport, housing, employment and social security programmes undermines policies which if, all working together, would support deaf and DDP to live independently. At the time of writing this issue remains unresolved.

### Mental Capacity

- 4.8.62 The Mental Capacity Act (2016) is non-compliant with the UNCRPD. The MCA Act (2016) provides for determinations of unfitness to plead and the defence of insanity which is representative of disability discrimination in context of the UNCRPD<sup>364</sup>. The Mental Health (NI) Order (1986)<sup>365</sup> provides for involuntary treatment of ‘mental disorder’, which is defined as ‘mental illness, mental handicap and any other disorder or disability of mind’ (MHO, Article 3(1)).<sup>366</sup>

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<sup>364</sup> Committee on the Rights of Persons with Disabilities (2014): General Comment No.1: Article 12: Equal recognition before the law. UN: CRPD/C/GC/1

<sup>365</sup> [The Mental Health \(Northern Ireland\) Order 1986 9](#) (accessed 12 March 2022)

<sup>366</sup> The MHO is accompanied by a short Code of Practice, and what is known as the [GAIN Guidelines](#), which set out detailed information about the provision of mental health care in line with the MHO.

## Mental Health

- 4.8.63 Mental health is recognised as one of the four most significant causes of ill health and disability in Northern Ireland along with cardiovascular disease, respiratory disease, and cancer.<sup>367</sup>
- 4.8.64 Northern Ireland is currently experiencing a mental health crisis.<sup>368</sup>
- 4.8.65 Northern Ireland has a higher prevalence of mental ill health (by 25%) and a lower per capita spend on mental health (£160) than England (£220) or Ireland (£200).<sup>369</sup> There is a significant funding gap in mental health provision.<sup>370</sup> There is a lack of provision for people experiencing mental health crisis.<sup>371</sup>
- 4.8.66 Health Minister Robin Swann launched the publication of the new Mental Health Strategy 2021-2031 on 29 June 2021.<sup>372</sup>
- 4.8.67 The strategy includes a commitment to provide enhanced and accessible mental health services for those who need specialist mental health services, including d/Deaf and disabled children and young people.

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<sup>367</sup> Wilson, G., Montgomery, L., Houston, S., Davidson, G., Harper, C. and Faulkner, L. (2015): [Regress? React? Resolve? An Evaluation of Mental Health Service Provision in Northern Ireland](#), page v

<sup>368</sup> The Irish Times (2021): [North braced for mental health crisis as a direct result of the pandemic](#), 29 June 2021

<sup>369</sup> ECNI (2021) [Response to the consultation by the Department of Health on the draft Mental Health Strategy 2021-2031](#), paragraph 1.27, p.6

<sup>370</sup> Belfast Telegraph (13 May 2021): [Mental health crisis: Patients are sleeping on chairs, says Swann](#)

<sup>371</sup> Ibid.

<sup>372</sup> DoH (2021): [Mental Health Strategy 2021-2031](#)

- 4.8.68 The strategy states that the services must be able to cater for those with disabilities, including physical and sensory disabilities, ASD and intellectual disabilities and must include help and support for parents and families.<sup>373</sup>
- 4.8.69 The strategy places an emphasis upon early intervention<sup>374</sup> and includes a commitment to develop an action plan which will include targeted approaches to groups more likely to be adversely affected by mental ill health including people with a physical or sensory disability and persons with an intellectual disability.<sup>375</sup> Progress has been limited by the political crisis.

### Social care

- 4.8.70 The crisis in social care funding and provision continues to have an adverse impact on DDP's right to independent living.
- 4.8.71 In common with other areas of healthcare, social care has been impacted negatively by short-term budgets. Community and voluntary providers are at the forefront of prevention and early intervention.<sup>376</sup> In spite of this the Department of Health has withdrawn funding from 62 organisations.<sup>377</sup> The cessation of this funding will place additional pressure on the health and social care system.
- 4.8.72 Northern Ireland is the midst of a health emergency arising from spiralling costs and the absence of Ministerial decision making and

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<sup>373</sup> Ibid, Action 7, VIII.

<sup>374</sup> Ibid, paragraph 45, p.26.

<sup>375</sup> Ibid, paragraph 54, p.31.

<sup>376</sup> <https://publications.parliament.uk/pa/cm201919/cmselect/cmniaf/300/30007.htm> para 91

<sup>377</sup> <https://www.newsletter.co.uk/health/department-of-health-funding-cuts-to-eviscerate-community-groups-throughout-province-4155869>

accountability. During the winter months patients were advised to discharge to care homes due to a shortage of care packages and the high volume of people in hospital. These actions have re-institutionalised DDP.<sup>378</sup>

- 4.8.73 The Department of Health have proposed restricting access to domiciliary care as a result of the public finance crisis. This will lead to the re-institutionalisation of DDP and further erode the health service.
- 4.8.74 The closure of the Independent Living Fund to new applicants has limited DDP's people's choice and control<sup>379</sup> in Northern Ireland.
- 4.8.75 The roll out of Self-Directed Support as a model to promote choice and control has been limited.<sup>380</sup> Access to appropriate social care packages and accessible housing have been recognised as the cornerstones of independent living.<sup>381</sup>
- 4.8.76 The demand for social care is increasing and access to funding is decreasing.<sup>382</sup> Disability Action recently conducted a small research study on Adult Social Care.<sup>383</sup>
- 4.8.77 There is an absence of information regarding the extent to which the needs of DDP with substantive needs and who are not in receipt of the

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<sup>378</sup> <https://www.belfasttelegraph.co.uk/news/northern-ireland/patients-urged-to-move-into-care-homes-to-address-hospitals-crisis/41085906.html>

<sup>379</sup> DfC (2020): [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#) p.34 (accessed 10 October 2021).

<sup>380</sup> Ibid, p.38.

<sup>381</sup> UKIM (2018): [Progress on disability rights in the United Kingdom](#), p.12 (accessed 10 October 2021).

<sup>382</sup> British Medical Association (2020): [Social care in Northern Ireland](#) (accessed 21 February 2022).

<sup>383</sup> McDonald, A. (2017): Is Adult Social Care Legislation and Policy Compliant with Article 19 of UNCRPD? Belfast: Disability Action.

Independent Living Fund payments are met by Self-Directed Support (SDS) and Direct Payment Provisions.<sup>384</sup>

- 4.8.78 Direct Payments do not fund many of the activities funded by the Independent Living Fund as the emphasis is upon addressing social care needs rather than promoting independence meaning that those in receipt have access to less support and have less control.<sup>385</sup>
- 4.8.79 The potential of direct payments to promote Independent Living has been hampered by cost savings to social care budgets.<sup>386</sup>
- 4.8.80 The reduced budget has resulted in the reduction in the provision of the provision of Disability Action Transport Services (DATS) by 5%.<sup>387</sup>
- 4.8.81 In the last 10 years DATS has provided 973,000 trips in all areas of Northern Ireland to older people and DDP of all ages to meet their daily needs to access; education, work, health appointments, essential shopping, and access to health and wellbeing activities.
- 4.8.82 The 5% reduction in DATs will reduce services reducing access to health appointments<sup>388</sup> and increasing pressure on transport services provided by the Department of Health. The reduction services

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<sup>384</sup> UKIM (2018): [Progress on disability rights in the United Kingdom](#), p.12

<sup>385</sup> IMNI (2017): [United Nations Convention on the Rights of Persons with Disabilities Jurisdictional 'Parallel' Report on Implementation in Northern Ireland: Working Paper](#), p.42

<sup>386</sup> Pearson, C. and Ridley, J. (2016): Is personalisation the right plan at the wrong time? Re-thinking cash-for-care in an age of austerity, *Social Policy and Administration*, 51 (7). pp. 1042-1059.

<sup>387</sup> <https://www.infrastructure-ni.gov.uk/news/department-infrastructure-outlines-final-budget-allocations-2023-24#:~:text=The%20Department's%20total%20resource%20requirement,when%20compared%20to%20last%20year.>

<sup>388</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/784685/future\\_of\\_mobility\\_access.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784685/future_of_mobility_access.pdf) p.12

available will reduce the ability of DDP to attend education thus reducing access to education services.<sup>389</sup> The reduction in services will prevent DDP from accessing employment.<sup>390</sup>

4.8.83 The Equality Impact Assessment published by DfI notes:

“Major potential impacts have been identified as a result of potential reductions to public transport and community transport. Older people, who normally make up approximately 20% of Metro passengers, 16% of NIR passengers and 13% of Ulsterbus passengers, and 57% of community transport users, require a service level to meet their normal daily needs which may include access to shops, friends and community facilities as well access to health and care services.”<sup>391</sup>

4.8.84 The removal of funding to Executive and New Decade New Approach commitments including the Disability Strategy by the Department for Communities<sup>392</sup> has resulted in the removal of funding for the development of a series of significant cross-departmental programmes/actions.

4.8.85 The Disability Strategy has been long sought by DDP. With respect to the proposed Disability Strategy the decision to remove funding for the Disability Strategy cross cuts all Departments as the Strategy proposes to address access to transport, the built environment, public

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<sup>389</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/784685/future\\_of\\_mobility\\_access.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784685/future_of_mobility_access.pdf) p.10

<sup>390</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/784685/future\\_of\\_mobility\\_access.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/784685/future_of_mobility_access.pdf) p.7

<sup>391</sup> <https://www.infrastructure-ni.gov.uk/sites/default/files/consultations/infrastructure/eqia-consultation-document-budget-2023-24.pdf> para 6.13, p.20.

<sup>392</sup> <https://www.communities-ni.gov.uk/sites/default/files/consultations/communities/dfc-budget-2023-24-eqia.pdf> p.17

services, access to culture, independent living, access to health and social care, access to employment, and access to education.<sup>393</sup> This severely undermines the rights of DDP.

- 4.8.86 The cancellation of the ‘Healthy Happy Minds’ primary schools counselling programme is a cut to mental health provision for children.<sup>394</sup>
- 4.8.87 Mental health challenges form the largest disability category in NI. Therefore, the ending of this programme disproportionately impacts upon disabled children.
- 4.8.88 The reduction of expenditure on community aids and adaptations for clients living in their own home and restrictions domiciliary care packages will disproportionately impact on DDP.<sup>395</sup> This will disproportionately impact upon DDP and older people and lead to the re-institutionalisation of DDP.

## **Independent living – Scotland**

### **National Care Service**

- 4.8.89 The National Care Service (Scotland) Bill was introduced into the Scottish Parliament on 20 June 2022. The Bill is a framework bill that lays the foundations for a national care service, allowing for the

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<sup>393</sup> DfC (2020): [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#),

<sup>394</sup> <https://pure.qub.ac.uk/en/publications/the-consequences-of-the-cuts-to-education-for-children-and-young-p.28>

<sup>395</sup> <https://www.disabilityaction.org/news/disability-action-response-to-the-department-of-health-budget-equality-impact-assessment>

substantive detail to be co-designed, primarily with people who access support, those who deliver it and unpaid carers, later.

- 4.8.90 In June 2023, for the second time MSPs voted to pause scrutiny of the Bill until January 2024.<sup>396</sup> Stakeholders raised concerns around how the service would work in practice and issues with the co-design process.
- 4.8.91 Push back against the Bill from various groups and disagreement means it is unlikely to have the weight it needs to change the system or deliver the transformational change that DDP had hoped for and which would help to progress our human rights.
- 4.8.92 Budget cuts are devastating social care support.<sup>397</sup> £22 million of cuts were made to the social care budget in Glasgow City Council alone.<sup>398</sup>
- 4.8.93 Eligibility criteria for access to social care support is based on ‘critical need’ excluding many people who require support. Criteria are based on a medical model, which restricts access to independent living.<sup>399</sup>
- 4.8.94 The Scottish Government’s commitment to scrap social care charges has not happened.<sup>400</sup> Care charges are going up and are completely unaffordable for many DDP. In some cases, people’s social care charges are going up by £200 a month.
- 4.8.95 In Glasgow, the Council can now take up to 75% of a person’s available income after housing costs. This is especially untenable during a cost of living crisis. As a result, people are trapped in their homes and are

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<sup>396</sup> [National Care Service now delayed until 2024 \(healthandcare.scot\)](https://healthandcare.scot)

<sup>397</sup> <https://ifs.org.uk/news/scottish-budget-2023-24-confirms-big-cuts-many-public-services>

<sup>398</sup> [Glasgow cuts £22m from health and social care services – BBC News](https://www.bbc.com/news/health-67444444)

<sup>399</sup> [Adult social care: independent review – gov.scot \(www.gov.scot\)](https://www.gov.scot/resources/documents/2023/06/Adult-social-care-independent-review.pdf)

<sup>400</sup> [Nicola Sturgeon pledges to scrap non-residential social care charges | The National](https://www.theguardian.com/scotland/2023/06/15/nicola-sturgeon-pledges-to-scrap-non-residential-social-care-charges)

being forced to make impossible decisions about heating, eating and using life saving/enhancing equipment.

### **Cuts to support**

- 4.8.96 Audit Scotland found ‘signs that the (social care) sector is in crisis, with growing backlogs, declining satisfaction and no clear picture of demand or unmet need’.<sup>401</sup>
- 4.8.97 Social Care delivery in Scotland faces a number of crises including inadequate resourcing,<sup>402</sup> high levels of vacancies,<sup>403</sup> and geographical variations in care costs.<sup>404</sup> However, there is no recognition of this by the Scottish Government. DDP are not able to live independently because of the crisis and Article 19 is not being realised in Scotland.
- 4.8.98 Recruitment and retention of staff in the social care support sector has become more difficult with key reasons for this being low pay and wage competition, a competitive job market and the UK’s EU Exit.<sup>405</sup>
- 4.8.99 Budget cuts and staff shortages are driving a culture which lacks empathy and fails to value lived experience and rights to full and equal participation in society. This makes working together, coproduction and codesign more challenging than ever.
- 4.8.100 DDPOs in Scotland have countless examples of DDP trapped in their homes and generally prevented from living a life of their choosing. One

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<sup>401</sup> [Local government in Scotland: Overview 2023 | Audit Scotland \(audit-scotland.gov.uk\)](https://www.audit-scotland.gov.uk/publications/2023/01/local-government-in-scotland-overview-2023)

<sup>402</sup> [Social care in Scotland \(bma.org.uk\)](https://www.bma.org.uk/social-care-in-scotland); [Demand and expenditure for adult social care in Scotland | FAI \(fraserofallander.org\)](https://www.fraserofallander.org/demand-and-expenditure-for-adult-social-care-in-scotland)

<sup>403</sup> [The 2021 Staff vacancies in care services report | Scottish Social Services Workforce Data \(sssc.uk.com\)](https://www.sssc.uk.com/the-2021-staff-vacancies-in-care-services-report);

<sup>404</sup> [Independent Review of Adult Care in Scotland \(www.gov.scot\)](https://www.gov.scot/independent-review-of-adult-care-in-scotland)

<sup>405</sup> Scottish Government (2022), [The Contribution Of EU Workers In The Social Care Workforce In Scotland 2022](https://www.gov.scot/the-contribution-of-eu-workers-in-the-social-care-workforce-in-scotland-2022)

example of this is a disabled woman fleeing domestic violence who was forced to live in a care home for a year because of lack of social care support in the community.

### **Self-directed support (SDS)**

- 4.8.101 Increased demand and limited budgets have put pressure on local authorities' ability to provide adequate SDS.<sup>406</sup>
- 4.8.102 When effectively implemented, SDS has positive outcomes but there is a lack of consistency in SDS provision,<sup>407 408</sup> as well as limited co-production, issues around workforce recruitment, training and awareness,<sup>409</sup> lack of transparency in recording decisions,<sup>410</sup> bureaucratic and unwieldy processes,<sup>411</sup> unequal access to independent advocacy and budgetary pressures.<sup>412</sup>
- 4.8.103 This has meant that the extent to which individuals have been able to access all four SDS options equally and exercise real choice and control has been stymied.
- 4.8.104 The Scottish Government published a new SDS Improvement Plan in June 2023 which will run from 2023-2027.<sup>413</sup>

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<sup>406</sup> Audit Scotland (2017), [Self-directed support: 2017 progress report](#)

<sup>407</sup> Care Inspectorate (2019), [Thematic review of self-directed support in Scotland: Transforming lives](#)

<sup>408</sup> The ALLIANCE and Self-Directed Support Scotland (2020), [My Support, My Choice: User Experiences of Self-directed Support in Scotland](#)

<sup>409</sup> [Self-directed support: 2017 progress report | Audit Scotland \(audit-scotland.gov.uk\)](#)

<sup>410</sup> [thematic-review-of-self-directed-support-in-scotland-transforming-lives.pdf \(careinspectorate.com\)](#)

<sup>411</sup> [Self-directed support: ten years on | Iriss](#)

<sup>412</sup> [Self-directed support: 2017 progress report | Audit Scotland \(audit-scotland.gov.uk\)](#)

<sup>413</sup> [Self-directed support: improvement plan 2023 to 2027 – gov.scot \(www.gov.scot\)](#)

## Mental Health

- 4.8.105 The Scottish Mental Health Law Review published its final report in 2022 and although it recommended a change in the language used in the Mental Health (Care and Treatment) (Scotland) Act (2003), it also recommended retaining the ability to detain people with learning disabilities in hospital on the grounds of a learning disability alone.<sup>414</sup>
- 4.8.106 This is despite long-standing opposition from DDPOs and Learning DDP's Organisations and recommendations from a previous review<sup>415</sup> that learning disability and autism should no longer be seen as a 'mental disorder' under mental health law.
- 4.8.107 Concerns have been raised about the inaccessibility of the review process and report and the inadequate involvement of people with lived experience.<sup>416, 417</sup>
- 4.8.108 In June 2023, the Scottish Government published a response to the review setting out its 'intended approach to delivery' including an early priority to 'work with partners to consider the definition of 'mental disorder' and reach a position on who should be within the scope of any future reformed Mental Health Act.'<sup>418</sup>

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<sup>414</sup> [Scottish Mental Health Law Review \(2022\), Final Report](#)

<sup>415</sup> The Independent Review of learning disability and autism in the mental health act (2019), [Final report](#)

<sup>416</sup> People First (Scotland) (2020), [People First Alternative Summary on the Scottish Mental Health Law Review](#)

<sup>417</sup> [SCLD-Response-to-SMHLR-FINAL-May-23.pdf](#)

<sup>418</sup> [Scottish Mental Health Law Review – Our Response \(www.gov.scot\)](#)

## Independent living – Wales

- 4.8.109 Disability Wales has welcomed the Welsh Government’s commitment to a National Care Service; however, we do not currently know what the proposed service would look like.
- 4.8.110 The Welsh Government published the £144 million Health and Social Care Regional Integration Fund, which will run from 2022-2027.
- 4.8.111 The fund seeks to create change using health and social care integration, over the five-year period they aim to have established six new national models of integrated healthcare.<sup>419</sup>
- 4.8.112 As the fund is relatively newly established and ongoing there is currently no data on its progress. Disability Wales has welcomed the Welsh Government’s commitment to a National Care Service;<sup>420</sup> however, we do not currently know what the proposed service would look like.

## 4.9 Institutionalisation and abuse

### Institutionalisation and abuse – England (WeG)

- 4.9.1 In January 2023, the BBC revealed widespread torture and abuse across several children’s care homes in Doncaster.<sup>421</sup>

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<sup>419</sup> Welsh Government, “Health and Social Care Regional Integration Fund Revenue Guidance 2022-2027”, 22<sup>nd</sup> February 2022,

<https://www.gov.wales/sites/default/files/publications/2022-02/health-and-social-care-regional-integration-fund-revenue-guidance-2022-2027.pdf>

<sup>420</sup> Welsh Government, “Establishing a National Care and Support Service for Wales”, 10<sup>th</sup> November 2022, <https://www.gov.wales/establishing-national-care-and-support-service>

<sup>421</sup> [Titheradge, N. \(2023\). Assaults, neglect and a Taser revealed in ‘deeply shocking’ BBC care home investigation. BBC News, \[online\] 13 April](#)

- 4.9.2 More than 100 reports of appalling abuse and neglect – dating from 2018 to 2021 – were uncovered at sites run by the Hesley Group. These included children being locked outside in freezing temperatures while naked, and having vinegar poured on wounds; children were beaten, under-fed and neglected.
- 4.9.3 Further intersectional discrimination was found in the care home shaving off the hair of disabled Black girls because staff were not prepared to learn how to care for it.<sup>422</sup>
- 4.9.4 Disabled children and young people are subjected to barbaric treatment in institutional settings which deny their human rights in many areas.
- 4.9.5 Abuse scandals within segregated settings for children and young people appear in the media but much more goes on that is not exposed with use of physical restraint and seclusion rooms common practice.<sup>423</sup>
- 4.9.6 The Independent Inquiry into Child Sexual Abuse (IICSA) has called for tougher inspection and oversight of residential special schools.<sup>424</sup>
- 4.9.7 Commentators have pointed to substantial profits made by companies delivering services where children are harmed. Hesley's accounts suggest the chief executive Chris McSharry has received at least £5m

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<sup>422</sup> [Harris, J. \(2023\). Learning-disabled and autistic people are being neglected and tortured. How much longer? \*The Guardian\*, \[online\] 24 April](#)

<sup>423</sup> [Titheradge, N. \(2021\). Pupil abuse in special school secure rooms filmed on CCTV. \*BBC News\*, \[online\] 14 October](#)

[Hattenstone, S. and Allison, E. \(2019\). 'He was covered in bruises': the vulnerable children being harmed in special schools. \*The Guardian\*, \[online\] 6 July](#)

<sup>424</sup> [Independent Inquiry into Child Sexual Abuse \(2022\). \*Residential schools investigation report\*. HC 1131, \[online\] March.](#)

since being made a director in 2006, and the Group recorded a 16% profit of £12m.<sup>425</sup>

- 4.9.8 Calcot Services for Children made profits of 36% in 2021 running homes, schools and supported living accommodation.<sup>426</sup> An investigation revealed children were harmed and assaulted while dedicated care and teaching staff were not provided despite receiving specific LA funding.
- 4.9.9 Abuse scandals at a number of adult institutions have resulted in large-scale criminal proceedings.
- 4.9.10 Undercover filming at Whorlton Hall showed staff intimidating, mocking and restraining patients with learning difficulties and autism. A police investigation was launched at the privately-run unit and 16 staff suspended.<sup>427</sup> Nine former staff members are due to face a five-week trial in 2023.<sup>428</sup>
- 4.9.11 In Essex psychiatric services, around 2,000 people died between 2000 and 2020 while on a mental health ward, or within three months of

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<sup>425</sup> According to the Care Quality Commission, 17% is “excessive”. It is thought Mr McSharry was aware of the ongoing abuse within the homes, as the BBC says it has seen “dozens” of emails from concerned family and staff members that were sent to the chief executive before the homes’ closure. [Nicolle, L. \(2023\). BBC investigation reveals more abuse at Hesley Group care homes. \*Learning Disability Today\*, \[online\] 14 April](#)

<sup>426</sup> [Titheradge, N. \(2023\). ‘Abuse, assaults and big profits’ – children’s homes staff speak out. \*BBC News\*, 6 June](#)

<sup>427</sup> Filming by the BBC's Panorama programme showed staff intimidating, mocking and restraining patients with learning difficulties and autism. Experts said the culture was deviant at the privately-run NHS-funded unit with evidence of "psychological torture". A police investigation has been launched and 16 staff suspended. [Trigg, N. \(2019\). Whorlton Hall: Hospital 'abused' vulnerable adults. \*BBC News\*, \[online\] 22 May](#)

<sup>428</sup> [Huntley, D. \(2021\). Nine former care workers to face trial in 2023 after denying patient abuse allegations. \*Chronicle Live\*, \[online\] 7 December](#)

being discharged. However, no inquiry was launched until 2021 and, because it had no legal status, the majority of staff refused to provide evidence. The inquiry has only been put on a statutory basis since June.<sup>429</sup>

- 4.9.12 Among many other scandals, there have been allegations relating to mental health services for teenagers run by the former Huntercombe Group;<sup>430</sup> claims uncovered by a BBC Panorama documentary about horrifying neglect and abuse at the Edenfield Centre near Manchester;<sup>431</sup> and the deaths of three teenage girls let down by “systemic failings and dangerous and coercive culture and practice” at services run by Tees, Esk and Wear Valleys NHS Foundation Trust.<sup>432</sup>
- 4.9.13 Behind these public scandals is a culture of mental health law which violates people’s CRDP rights and a culture of inhuman and degrading treatment which is in very serious breach of CRDP Article 15.
- 4.9.14 Based as it is on record-keeping, the rapid review which the government initiated to look into safety in psychiatric hospitals has come nowhere near addressing what is needed. Whether the forthcoming national investigation<sup>433</sup> will do so depends hugely on the

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<sup>429</sup> Precey, M. (2023). Essex mental health deaths inquiry given legal powers. BBC news [online], 28 June. Available at: <https://www.bbc.co.uk/news/uk-england-essex-66044321>

<sup>430</sup> [Holland, L. and Lucas, R. \(2022\). 'Treated worse than animals': Huntercombe investigation reveals decade of mistreatment in care of more than 20 teenagers. Sky News, \[online\] 27 October](#)

<sup>431</sup> [BBC News \(2022\). Edenfield Centre: Hospital's 'toxic culture' of abuse exposed. \*bbc.co.uk\*, \[online\] 28 September](#)

<sup>432</sup> [Volpe, S. \(2022\). North East teens tragically took their own lives after 'appalling' NHS mental health care. \*ChronicleLive\*, \[online\] 2 November](#)

<sup>433</sup> [Thomas, R. \(2023\). Health secretary launches national investigation into NHS mental health scandals after Independent exposes. \*Independent\* \[online\], 28 June](#)

approach taken and the influence which people with psychosocial and intellectual disabilities have over it.

- 4.9.15 Campaigners are urging WeG to recognise that only full-scale compliance between mental health legislation and the CRDP will achieve the fundamental changes needed.<sup>434</sup>

### **Institutionalisation and Abuse – Northern Ireland**

- 4.9.16 The severity of the cuts in NI is eroding the right to independent living of disabled and essential services are being eroded and picked apart. The proposed decision of the Department of Health to restrict access to domiciliary care has institutionalised DDP.
- 4.9.17 NI continues to employ legislation entrenched in a medical as opposed to a human rights approach and which authorises substitute decision-making, detention in psychiatric institutions, involuntary treatment and the use of community treatment orders.
- 4.9.18 This includes the non-progression of the commitment of the UK Government to legislate for a Bill of Rights for NI. DDP continue to have no right to independent living enshrined in domestic legislation.
- 4.9.19 The lack of appropriate independent living support provision places DDP at increased risk of abuse and exploitation including the inappropriate use of restraint and seclusion.<sup>435</sup>
- 4.9.20 The potential for abuse is greater within institutional settings as demonstrated by the launch of a Public Investigation into events at

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<sup>434</sup> [Pring, J. \(2023\) 'Halt new mental health bill until there is a public inquiry into deaths and abuse' Disability News Service, \[online\] 26 January](#)

<sup>435</sup> <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/UNCRPD%20investigations/UNCRPD-Implementation-NI-Summary.pdf>

Muckamore Abbey Hospital<sup>436</sup> and the Older Person's Commissioner's report on Dunmurry Manor<sup>437</sup> both of which include evidence of violence against and the abuse of DDP.

- 4.9.21 The Health Minister Robin Swann pledged to bring forward a new Adult Safeguarding Bill for NI, to help protect care home residents and other vulnerable people<sup>438</sup>. This has not progressed due to the absence of functioning political institutions in NI.
- 4.9.22 Disability Action are aware of cases in which DDP have been abused and in spite of evidence including CCTV footage, cases have not proceeded to court due to the Public Prosecution Service questioning whether a person who is non-speaking can articulate impact.

### **Institutionalisation and abuse – Scotland**

- 4.9.23 DDPOs in Scotland have countless examples of DDP trapped in their homes and generally prevented from living a life of their choosing. One example of this is a disabled woman fleeing domestic violence who was forced to live in a care home for a year because of lack of social care support in the community.
- 4.9.24 Many people with a learning disability still do not have choice and control over where they live and who they live with. Scottish DDPOs know of cases where people have been told that if their support needs are too high then they need to live with other people – people that they do not know or have not chosen to live with.

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<sup>436</sup> DoH (2020): [Muckamore Abbey Hospital – Public Inquiry](#)

<sup>437</sup> COPNI (2020): [Commissioner for Older People concludes his Home Truths investigation into Dunmurry Manor Care Home](#)

<sup>438</sup> DoH (2020): [Minister announces plans for Adult Safeguarding Bill for Northern Ireland](#)

- 4.9.25 The Scottish Government’s commitment to reducing the number of people with learning disabilities and complex care needs living in hospitals<sup>439</sup> is too vague and will not be achieved by March 2024 – much of the implementation work has been around putting more policies and processes in place.
- 4.9.26 We are concerned that the focus is not on the person themselves and their rights.
- 4.9.27 We are further concerned that Scottish Government funding may be being used to develop plans for ‘core and cluster’ housing for people being moved out of hospital. Moving people into such housing still amounts to institutionalisation by ghetto-isation.

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<sup>439</sup> [Coming Home Implementation: report from the Working Group on Complex Care and Delayed Discharge 2022 – gov.scot \(www.gov.scot\)](#) – followed publication of [Coming home: complex care needs and out of area placements 2018 – gov.scot \(www.gov.scot\)](#)

## 5. Disability Narratives

- 5.1 WeG has not fulfilled the Committee’s recommendation to combat negative stereotypes of benefit claimants. WeG has never acted to challenge false public perceptions of high levels of benefit fraud.
- 5.2 Reports of disability hate crime have risen both on and off line while prosecutions have remained low.
- 5.3 Hate crime rose in England and Wales by 9% between 2019 and 2020 and by 14% from 2017 – 2019.<sup>440</sup>
- 5.4 A WeG Parliamentary inquiry into online hate crime against Disabled people heard how DDP were leaving social media due to abuse and found that “Self-regulation of social media has failed disabled people”.<sup>441</sup>
- 5.5 DDP report being affected by a narrative that emerged during the pandemic that their lives are expendable.<sup>442</sup> Political and public debate opened up questions about relative worth presenting a choice between lockdowns to protect the “vulnerable” versus prioritising the economy.
- 5.6 Media attention and official responses linked disproportionate deaths of DDP to underlying health conditions. Messaging gave the impression of a distinction between these deaths and those of non-disabled people. There was no public or political outcry against disproportionate DDP mortality statistics.
- 5.7 A blog post on The Health Foundation website comments:

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<sup>440</sup> [Home Office \(2019\). \*Hate Crime, England and Wales, 2018/19\*. \[online\], 15 October.](#)

<sup>441</sup> [Petitions Committee \(2019\). \*Online abuse and the experience of disabled people\*. HC 759, 22 January](#)

<sup>442</sup> [Inclusion London \(2022\). \*Westminster Government Shadow Report: Annex A – Our Voices\* \[online\] pp. 78-80](#)

“There has been a surprising absence of analysis of the reasons for this particular inequality... The category of ‘underlying health conditions’ has been used prominently, including in press briefings and analysis, with little reference to ‘disability’... Explaining deaths in terms of underlying health conditions omits reference to co-occurring risk factors.”<sup>443</sup>

- 5.8 DDPOs are concerned that since the start of the pandemic attitudes towards disabled people have deteriorated further. The rhetoric of politicians and in the media around who was at risk from the virus and who would be prioritised for ventilation made DDP feel expendable and frightened to go to hospital.<sup>444</sup>
- 5.9 The cost of living crisis has also seen a deterioration in attitudes towards DDP in receipt of benefits, reminiscent of those seen when the Committee conducted its Inquiry in 2016.<sup>445</sup>
- 5.10 In March 2023, WeG Chancellor launched his “back-to-work” budget focused on tackling “economic inactivity”.<sup>446</sup> Since then, political rhetoric has fired up against benefit fraud in an aggressive way.<sup>447</sup>

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<sup>443</sup> [Sayce, L. \(2021\). The forgotten crisis: exploring the disproportionate impact of the pandemic on disabled people. \*The Health Foundation\*, 21 February](#)

<sup>444</sup> [healthandcare.scot \(2020\). \*Disabled people still fear treatment denial. healthandcare.scot \[online\]\* 22 May](#)

[Hoskin, J and Finch, J. \(2020\). \*Covid-19, disability and the new eugenics: Implications for social work policy and practice. SW2020-21 Covid019\*, Fourth Edition, \[online\] 2 June](#)

<sup>445</sup> [Ryan, F. \(2023\). \*A decade after the Tories demonised disabled people on benefits, it’s happening again. The Guardian\*, \[online\] 30 May](#)

<sup>446</sup> [HM Treasury and Hunt, J. \(2023\). \*Spring Budget 2023 speech\*. \[online\] 15 March](#)

<sup>447</sup> [Pring, J. \(2023\). \*‘Miniscule’ benefit fraud stats ‘show minister’s hostile video was shameful and disablist. Disability News Service\*, \[online\] 18 May.](#)

5.11 There were calls for WeG’s current Minister for Disabled People, Tom Pursgrove, to resign when he posted on social media a parody of a speech from a violent film. In the video he wears a stab-proof vest with the letters “DWP”. The video starts with blue flashing lights and police sirens and he says to the camera: “We will track you down. We will find you. And we will bring you to justice.” The post linked to a news story about allegations of disability benefit fraud.<sup>448</sup>

5.12 The broadcaster Jeremy Vine is facing angry calls for a personal apology after a member of his team published a social media post in his name that asked if it was time to “crack down” on sick and disabled people on out-of-work benefits.<sup>449</sup>

5.13 The post from the “Jeremy Vine on 5” account said:

“Is it time to crack down on jobless benefits? Nearly four million people in the UK are being supported by the state without ever having to look for a job. That’s because they’ve been deemed too sick to work. Is it wrong for taxpayers to fund them indefinitely?”<sup>450</sup>

5.14 Among a series of articles attacking disability benefit claimants, one newspaper created an online calculator for readers to work out how much of their taxes are spent on the social security system.<sup>451</sup>

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<sup>448</sup> [Pring, J. \(2023\). ‘Miniscule’ benefit fraud stats ‘show minister’s hostile video was shameful and disablist. \*Disability News Service\*, \[online\] 18 May.](#)

<sup>449</sup> [Pring, J. \(2023\). \*Broadcaster’s silence over ‘rabblouser’ tweet on disability benefits.\* \*Disability News Service\*, \[online\] 1 June](#)

<sup>450</sup> Ibid.

<sup>451</sup> [Clark, A and Haynes, T \(2023\). \*Exactly how much of your salary goes towards Britain’s growing welfare state.\* \*The Telegraph\*, \[online\] 12 June.](#)

- 5.15 According to DWP’s own figures for 2022-23, estimated Personal Independence Payment (PIP) fraud was just 0.2 per cent of PIP spending and Employment and Support Allowance (ESA) fraud 1.5% of ESA.<sup>452</sup>
- 5.16 The £40 million lost to PIP fraud compares with an estimated £60 million in underpayments of PIP caused by DWP error in 2022-23.<sup>453</sup>
- 5.17 Hate crime law is still not equal for disability.
- 5.18 DDP are calling for all protected characteristics including disability to be included in the Public Order Act 1986 under “stirring up offences”. If this was the case the above examples of political and media targeting of disabled benefit claimants would arguably be unlawful. The Public Order Act 2023 sets out new “offences” limiting the right to peaceful protest and does not address the inequality in hate crime law.
- 5.19 DDPOs also argue the need for anti-hate legislation that captures crimes motivated by reason of a person being disabled. Currently perpetrators need to have shown hostility towards a person’s disability for it to count as a hate crime which excludes deliberate targeting and exploitation of DDP.
- 5.20 There is also a lack of legislation for dealing with intersectional discrimination.

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<sup>452</sup> [DWP \(2023\). \*Fraud and error in the benefit system: financial year 2022 to 2023 estimates\*. \[online\] 11 May](#)

<sup>453</sup> Ibid.

## 6. Barriers to justice

- 6.1 In order to challenge WeG legislative and policy measures that retrogress the rights of DDP, individuals who are personally affected need to initiate legal challenges “not later than three months of the after the grounds to make the claim first arose”. The difficulty of this means discriminatory and unlawful decisions frequently go un-challenged.
- 6.2 Tightened financial eligibility rules for legal aid funding in England and Wales have contributed to the barriers to bringing judicial reviews.
- 6.3 Nevertheless, judicial review has played a very important role in enabling DDP to challenge decisions that would lead to retrogression of our rights, living standards and ability to participate in society – decisions which WeG was not interested in hearing and/or not willing to amend in light of the adverse impacts they would have. See Appendix 4 for a list taken since 2016.
- 6.4 Access to justice is a devolved issue for Scotland and Northern Ireland and reserved for Wales. The picture across the four nations is different.
- 6.5 Millions of people in England and Wales now live in areas where they can no longer access the help and advice that Parliament has said they are entitled to.
- 6.6 Across England and Wales:
- 53m people (90%) do not have access to a local education legal aid provider
  - 49.8m people (84%) do not have access to a local welfare legal aid provider
  - 42m people (71%) do not have access to a local community care legal aid provider

- 39m people (66%) do not have access to a local immigration and asylum legal aid provider
- 25.3m people (42%) do not have access to a local legal aid provider for housing advice, a figure that has grown 5% since 2019<sup>454</sup>

6.7 In 2018, the EHRC found: “access to justice has deteriorated” in England and Wales.<sup>455</sup>

6.8 WeG’s long-awaited Legal Aid, Sentencing and Punishment of Offenders Act 2012 (LASPO) review and associated Action Plan were disappointing in offering no immediate improvement.

6.9 Nothing was included about reinstating legal aid for initial welfare advice and employment claims despite clear evidence that the lack of support to resolve legal issues has negative impacts on emotional, social, financial and mental health. WeG committed to reviewing thresholds for legal aid but there is no guarantee they will up them.<sup>456</sup>

6.10 Ten years after the introduction of LASPO, justice is increasingly out of reach for those in most need, as evidenced by new maps from the Law Society of England and Wales showing expanding legal aid deserts.<sup>457</sup>

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<sup>454</sup> Ibid.

<sup>455</sup> [EHRC \(2018\). \*Is Britain Fairer? The state of equality and human rights in Britain.\* \[online\], p.5.](#)

<sup>456</sup> [MoJ \(2019\). \*Post-Implementation Review of Part 1 of the Legal Aid, Sentencing and Punishment of Offenders Act 2012 \(LASPO\).\* CP 37, \[online\] February ; MoJ \(2019\). \*Legal Support: The Way Ahead – An action plan to deliver better support to people experiencing legal problems.\* CP40, \[online\] February ; EHRC \(2019\). \*The impact of LASPO on routes to justice, research report 118.\* \[online\]](#)

<sup>457</sup> [The Law Society \(2023\). \*A decade of cuts: Legal aid in tatters.\* \[press release\] 27 June](#)

- 6.11 The number of legal aid cases to help people get the early advice they need dropped from almost a million in 2009/10 to just 130,000 in 2021/22.
- 6.12 Over the same period the number of people having to go to court without representation trebled.
- 6.13 Legal aid for welfare cases has not been reintroduced.
- 6.14 Law centres across the country closed down.
- 6.15 LA complaints procedures are difficult to navigate. There remains no appeals process under the Care Act. The EHRC found the system of challenging social care decisions confusing and subject to long delays.<sup>458</sup>
- 6.16 The availability of community care lawyers to challenge LA decisions over cuts to social care support has drastically reduced due to legal aid cuts. Two thirds of social care users do not have access to professional legal advice.<sup>459</sup>

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<sup>458</sup> [EHRC \(2023\) \*Challenging Adult Social Care Decisions in England and Wales\*. \[online\]](#)

<sup>459</sup> [The Law Society \(2022\), \*Community care – legal aid deserts\*. \[online\]](#)

## 7. Engagement

- 7.1 Engagement is devolved. See Section 4 above.
- 7.2 On reserved issues, WeG sets UK-wide policies. Its engagement with DDPOs on these issues should also be UK-wide but this does not happen.
- 7.3 WeG has a tendency to dismiss any criticism of its policies.<sup>460</sup> This is why we need to evidence our submissions so thoroughly – in order to minimise chances to discredit our reports as politically motivated rather than evidence based.

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<sup>460</sup> As highlighted in the following: [National Audit Office \(2018\). \*Rolling out Universal Credit\*. HC 1123, 2017–2019, \[online\] 15 June](#), p.8 ; [WPSC \(2019\). \*Universal Credit and “survival sex”\*. HC 83, \[online\] 16 October](#), p.43 ; [Alston, P. \(2018\). \*Statement on Visit to the United Kingdom\*. \[online\]](#), p.5.

## 8. Monitoring, statistics and data gaps

- 8.1 There has been a reduction in disability data collection by WeG preventing scrutiny. The depth and robustness of the evidence that triggered the Special Inquiry can no longer be replicated due to missing information.
- 8.2 WeG's 2023 Disability Action Plan includes plans to improve data collection. Better research into the experiences of DDP is mentioned. This is welcome but must not be instead of robust and transparent quantitative data that can be used to hold WeG to account.
- 8.3 We are seriously worried about the lack of UC disaggregated sanctions data which WeG chooses to publish. This makes it impossible to tell if the conditionality regime continues to discriminate against Deaf and disabled claimants with sanctions now being ramped up.
- 8.4 The combination of in-work conditionality and WeG proposals to replace ESA with a UC health element determined by the PIP assessment mean that around 956,000 DDP could disappear from visibility within UC.<sup>461</sup>
- 8.5 DWP has tried to block publication of a number of reports relevant to the impact of its policies on DDP.<sup>462</sup> Researchers report being told to water down their findings. This contributes to a lack of trust.
- 8.6 WeG social security policies and general approaches continue to lack scientific evidence base. The idea that DDP who are not in work can fill the high number of job vacancies in the UK since EU withdrawal is purely ideological with no attempt to cross reference with health data.

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<sup>461</sup> On the basis of 27% of the 1.2 million people in the "light touch" group affected by in-work conditionality added to 632,000 people in receipt of ESA now who do not qualify for PIP.

<sup>462</sup> For example, on the experiences of "vulnerable" claimants, on the impacts of sanctions and on the experiences of former Independent Living Fund recipients.

8.7 A former Work and Pensions Secretary of State recently wrote in *The Telegraph*:

“Stop sick people from languishing on benefits, – with the right incentives, they can fill vacancies and end our country’s reliance on cheap foreign workers”.<sup>463</sup>

8.8 Underpinning social security policy appears to be a disbelief that the overwhelming majority of those claiming disability benefits are genuinely disabled and face material barriers to paid employment.<sup>464</sup>

8.9 The fact that we are genuinely disabled is confirmed by the very low DWP fraud figures. This is in spite of DWP surveillance and their benefit fraud hotline.

8.10 WeG planned to reduce spending on extra costs disability benefits by 20% when PIP was introduced to replace DLA. In 2019 it was reported that instead, DWP was over-spending. WeG’s analysis cites factors such as “legal challenges” and “social media” contributing to this.

8.11 A rise in disability prevalence, fall in real terms wages and growth in financial insecurity are not mentioned. The implication is that the rise in claims and higher awards are not genuine.

8.12 Many different factors including WeG’s own legislative and policy measures since 2010 are contributing to increasing disability prevalence.

8.13 According to the 2021 Census, among some younger age groups, there was an increase in disability prevalence not seen in previous censuses. For females aged 15 to 19 years, the percentage of disability was 12.2% in

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<sup>463</sup> [Duncan Smith, I. \(2023\). Stop sick people from languishing on benefits. \*Telegraph\*, \[online\] 24 May.](#)

<sup>464</sup> [Office for Budget Responsibility \[OBR\], \(2019\). Welfare Trends Report. \[online\] pp. 14 and 89-90](#)

2021; 7.6 percentage points higher than in 2011 and 7.3 percentage points higher than in 2001. This continued into the 20 to 24 years age group, where disability prevalence increased from 5.2% in 2011 to 15.1% in 2021. For males, the increased prevalence of disability in 2021 began at earlier ages; 8.4% of males aged 5 to 9 years were disabled in 2021, compared with 5.0% in 2011 and 5.4% in 2001.<sup>465</sup>

8.14 There are no plans to understand this rise as far as we are aware.

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<sup>465</sup> [ONS \(2023\). Disability by age, sex and deprivation, England and Wales: Census 2021. \[online\] 8 February](#)

## 9. Non-social/human rights model

- 9.1 WeG’s work and social security policies continue to be underpinned not by a social/human rights model approach but by a biopsychosocial one.<sup>466</sup>
- 9.2 This is evident by changes in DWP language: they no longer talk about DDP on income replacement benefits but instead about “claimants on a health journey”; ESA is being replaced by a UC “health” element.
- 9.3 DWP is redefining disability where disability is not according to the Equality Act definition but whether a person has been found to have limited capability for work or for work related activity through one of their functional assessments.
- 9.4 This is evident in how WeG’s equality analysis for In-work Progression assesses that only 1.1% off those affected by the policy are disabled on the basis that that is the percentage of the relevant caseload who will be awaiting the outcome of a WCA. It does not include disabled claimants who have not gone through a WCA, who are in work and/or who have been found fit for work are not included. The 2021 DWP Future Cohorts Study calculated that 27% of the caseload affected by IWP are disabled on the basis of self-identification of a study sample according to the Equality Act definition.<sup>467</sup>

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<sup>466</sup> Specifically, by the Waddell-Aylward biopsychosocial model of disability. See p.66

<sup>467</sup> [DWP \(2023\). \*Equality Analysis: In-Work Progression Offer\*. \[online\] 17 April.](#)

## 10. CRDP Importance

- 10.1 The CRDP has great importance to UK DDP. It is a benchmark against which to defend our rights and a vision of hope for the future.
- 10.2 Such is the level of interest in the CRDP that the compilation of shadow reports has become a broad collective effort across UK nations, between DDPOs and allies and informed by input from thousands of individual DDP.
- 10.3 We are aware how governments share information. Policy trialled on DDP in the UK influences policies then inflicted on DDP in other areas of the world and vice versa.
- 10.4 For example, “deeming” laws and practices in Canada have close similarities with the WCA where the views of medical professionals treating the claimant are dismissed by assessors employed within a programme underpinned by an ideological assumption that people are “better” or “fixed” through employment, effectively denying disability.
- 10.5 We believe the UK is the first country in the world to introduce in-work conditionality. Extending conditions and support to working social security claimants (through Universal Credit) has been described as ‘ground-breaking’ with ‘no comparable precedents’.<sup>468</sup>
- 10.6 The special inquiry is important in highlighting the human cost of measures introduced here.
- 10.7 In England DDP are campaigning for the CRDP to be enshrined in domestic legislation.

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<sup>468</sup> [Social Security Advisory Committee \(SSAC\) \(2017\) \*In-work progression and Universal Credit: A study by the Social Security Advisory Committee Occasional Paper No. 19.\*](#)

10.8 The current consultation on a new human rights law for Scotland, which includes incorporating the CRPD into Scots law, provides the opportunity to move from rhetoric to action. DDPOs and civil society fully support the introduction of a new human rights law which will ensure the strongest protection possible with accessible routes to justice, as well as the necessary resources and support to effectively implement a culture of human rights in Scotland.

# Appendices

# Appendix 1:

## Some examples of the Human Cost

### Individual Cases

#### **February 2023**

The body of a disabled woman lay undiscovered in her flat for more than three years after the Department for Work and Pensions (DWP) cut off her disability benefits, her family say.

Laura Winham's body was not found until May 2021, more than three-and-a-half years after she was last seen alive.

<https://www.disabilitynewsservice.com/dwp-failings-linked-to-death-of-claimant-whose-body-lay-undiscovered-for-years/>

#### **November 2022**

A disabled woman left traumatised by the daily demands of the universal credit system took her own life just four days after being told she would need to attend a face-to-face meeting with a work coach, her family say.

<https://www.disabilitynewsservice.com/woman-took-her-own-life-after-trauma-caused-by-daily-demands-of-universal-credit/>

## October 2022

The Department for Work and Pensions (DWP) has admitted repeatedly breaching the Equality Act, after a disabled man was left needing hospital treatment three times for suicidal thoughts caused by months of failures by universal credit advisers and jobcentres.

<https://www.disabilitynewsservice.com/dwp-admits-court-defeat-after-universal-credit-discrimination-led-to-suicide-thoughts/>

## June 2022

A severely distressed disabled man who repeatedly warned Department for Work and Pensions (DWP) staff that his life was at risk says they refused to take action to protect him, breaching their own guidance on suicidal benefit claimants.

<https://www.disabilitynewsservice.com/dwp-ignored-five-weeks-of-pleas-for-help-from-suicidal-claimant/>

## February 2022

A disabled woman, Sophia Yuferev, whose body was found in her flat months after all her benefits had been removed had been hounded for years by the Department for Work and Pensions (DWP), and repeatedly failed by other public bodies, documents have shown.

<https://www.disabilitynewsservice.com/dwp-hounded-disabled-woman-for-years-before-her-starvation-death-papers-show/>

## 2019

A coroner failed to investigate how the actions of the Department for Work and Pensions (DWP) may have been a factor in a disabled man's death, despite twice being told that there was evidence of such a link.

<https://www.disabilitynewsservice.com/coroner-failed-to-investigate-dwp-links-to-death-of-pip-claimant/>

## November 2018

UN expert has heard how a man with learning difficulties died a month after attempting to take his own life, following a move onto the government's "chaotic" universal credit benefit system that left him hundreds of pounds in debt.

<https://www.disabilitynewsservice.com/chaotic-universal-credit-led-to-disabled-mans-death-sister-tells-un-poverty-expert/>

# Evidence of on-going systemic abuse

## July 2022

The Department for Work and Pensions (DWP) has dismissed new research that for the first time brings together more than 30 years of evidence that links its systemic failings with the deaths of countless disabled claimants of benefits.

<https://www.disabilitynewsservice.com/dwp-dismisses-300-pages-of-evidence-linking-its-actions-with-countless-deaths/>

## November 2022

Disabled activists who have spent years raising concerns about universal credit have warned of its cruelty and how the system “hounds” claimants into complying with strict rules.

They spoke out this week as Disability News Service (DNS) reveals how a disabled woman took her own life after she was left traumatised by the daily demands of universal credit and its online journal.

<https://www.disabilitynewsservice.com/universal-credit-chaos-fear-and-preventable-deaths/>

## December 2022

Disabled campaigners have expressed shock and anger after learning how the Department for Work and Pensions (DWP) secretly abandoned work on a £106 million plan that was supposed to help it prevent further deaths of benefit claimants.

<https://www.disabilitynewsservice.com/shock-and-anger-over-dwps-despicable-decision-to-abandon-work-on-deaths-plan/>

## April 2023

Extracts from new secret reports show a catalogue of errors made by the Department for Work and Pensions (DWP) and its private contractors that have been linked to the deaths of disabled people interacting with the benefits system.

<https://www.disabilitynewsservice.com/new-inquiry-call-as-dwp-deaths-mount-despite-decade-of-secret-investigations/>

## April 2023

Systemic safeguarding flaws across the Department for Work and Pensions (DWP) have been linked by its own civil servants to the deaths of multiple benefit claimants between 2018 and 2020, secret reports have revealed.

<https://www.disabilitynewsservice.com/secret-dwp-reports-link-more-deaths-with-systemic-flaws/>

## May 2023

The Department for Work and Pensions (DWP) is blocking the release of a paper that details the impact of its own errors on disabled people whose deaths are likely to be linked to its failings and policy decisions.

<https://www.disabilitynewsservice.com/dwp-blocks-release-of-report-on-impact-of-its-errors-on-vulnerable-claimants/>

## July 2023

MPs are to launch an inquiry into safeguarding arrangements at the Department for Work and Pensions (DWP), following countless deaths of disabled benefit claimants linked to its actions and failings over more than a decade.

<https://www.disabilitynewsservice.com/mps-launch-inquiry-into-dwp-safeguarding-after-decade-of-deaths/>

# Death by neglect in the community

## Debbie Leitch

<https://www.dailyrecord.co.uk/news/crime/evil-mum-starved-disabled-daughter-26323021>

Elaine Clarke, 49, admitted killing her daughter Debbie Leitch, who had Down's Syndrome, and was convicted of gross negligent manslaughter.

The 24-year-old died from severe emaciation and neglect after with Clarke "abandoned her to die in pain, without nourishment in the most awful surroundings", judge Amanda Yip said.

When emergency services discovered Debbie inside her house in Blackpool, Lancashire, on August 29, 2019, she wasn't immediately "recognisable as a woman" as her face was so badly crusted.

Her emaciated body was in a room covered in maggots and dried faeces on the floor, with a post-mortem examination finding that she had an extensive scabies skin infection

Her hair was falling out. Scabies mites had been allowed to breed and multiply. Her skin was crusted.

On one occasion, the same family member told the court that they saw Debbie at home wearing dirty and rotting pyjamas, her hair appeared to have been hacked off and her skin was cracked.

She described Debbie as looking 'half-dead' to police, and found her lying on filthy bed sheets with dirty nappies around her.

When she confronted Clarke about it, she seemed uninterested in the conversation, and the family member said she seemed only interested in claiming benefits for Debbie.

At a later date, Clarke cleaned up the house and scrubbed Debbie in an "excruciating" shower to cover up her treatment of her daughter.

A carer from Cherish UK, who was visiting one of Debbie's siblings, said she could hear Debbie crying for her mum from another room, and neighbours also reported hearing her in the days before her death.

On the day Debbie died, Clarke called an ambulance and told them her daughter had died.

When ambulances arrived they were struck by the smell in Debbie's bedroom, which the court was told was like something decomposing.

## Kaylea Titford

[https://en.wikipedia.org/wiki/Killing\\_of\\_Kaylea\\_Titford](https://en.wikipedia.org/wiki/Killing_of_Kaylea_Titford)

On 10 October 2020, Kaylea Louise Titford was found dead in her house in Newtown, Powys, Wales. She had turned 16 years old on September 27,[4] and was born with spina bifida, leaving her reliant on a wheelchair. When her death was discovered, she had been "left to die" in unsanitary conditions found by the court to be "unfit for any animal". The room was full of rubbish and fly faeces surrounded by soiled houstraining pads for dogs and uncollected bottles of urine from her catheter. When police officers moved her body, there were flies and maggots where she had once been lying and in her bedding. The night of her death, she had repeatedly called her parents for help only to be told to stop screaming. At her death, she weighed 22 stone 13 pounds (321 lb; 146 kg) and had a body mass index of 70, making her morbidly obese. The court found that her death was caused by gross negligence from her parents.

During the COVID-19 lockdown, between March 2020 and the date of her death, she was restricted to bed by and reliant on her parents for help. During this period, she was largely left on her own, going without

showering for several months and defecating in her own bed. She was fed a diet largely made of fast food which contributed to her obesity. She and her sister called for help to deal with the flies, the general filth and for toileting assistance in multiple text messages the weeks prior to her death.

# Appendix 2:

## Universal Credit policy and administration in the UK

Drawing from CPAG analysis, including July 2021, [Universal Credit: What needs to change?](#)

### Background

Universal Credit (UC) is the main welfare benefit administered by the DWP, largely replacing a range of previous benefits for housing, out-of-work benefit, and income supplement for those in work.

The level of benefit available under UC, along with its structure and the administration of the benefit, create a hostile environment for anyone needing to claim their UC entitlement.

While UC is reserved to the UK Government, there are differences in Scotland, giving the options of receiving UC payments twice a month rather than monthly; or having the UC housing element being paid directly to the landlord.

### Issues with UC – policy and structure

**Level of UC:** The standard allowance within UC is intended to cover daily living costs for working age adults (excluding housing, children, disability). A single person aged over 25 receives £368.74 monthly.

In the context of the cost of living crisis, UC is paid at poverty levels and doesn't protect people from destitution.

**Taper rate:** When an employed claimant earns more than the monthly ‘work allowance’, their UC is clawed back at a rate of 55p per pound earned (previously 63p).

**Benefit cap:** The benefit cap limits the amount low-earning and non-employed households can receive through UC, regardless of need.

While the cap on benefit payable through UC was uprated in the Spring 2023 budget (for the first time since the cap was lowered in 2016), there were still projected to be 100,000 households affected by the cap in April 2023.

**Two child limit:** The two-child limit stops families with a third or subsequent child born after 6 April 2017 from receiving up to a further £2,845 in support. An exception is made if additional children are conceived of rape; this involves the rape survivor making an application to that effect to DWP.

In 2023/24 over 1.5 million children live in households affected by the policy. The policy has been shown to have a negligible impact on the number of children parents decide to have.

**Young Person penalty:** UC introduced a new cut in support for the under 25s, as the lower rate also applies to younger parents. Under UC, single parents under 25 receive around £65 less each month, and couple parents receive £100 less.

In 2019/20, 45 per cent of parents aged under 25 were in poverty, almost double the poverty rate among older parents (24 per cent).

**Household rather than individual entitlement:** UC is paid into a single nominated bank account for a household. This raises concerns about making financial abuse easier, and being unsuited to the varying circumstances of couples.

Only in “exceptional circumstances”, such as domestic violence or financial abuse, can a split payment be arranged – which involves the abuse survivor making an application to that effect to DWP.

**Paid monthly in arrears:** The system of monthly earnings assessment means that UC awards can be unpredictable for those paid weekly, fortnightly or four-weekly, even when their underlying earnings patterns have not changed.

Receiving an additional pay cheque in a single UC assessment period causes the UC award to drop significantly, making budgeting difficult.

**Five week wait:** After their application for UC a person must wait a minimum of five weeks before receiving their first payment – about three weeks longer than the initial period for other elements of social security.

DWP offers an advance payment to support claimants in the waiting period. This is a loan, and repayments are deducted from subsequent UC payments. For many this merely delays the financial pressure.

**Deductions:** As well as deductions to repay an advance payment, other direct deductions can be made to a person's UC entitlement. For example, in case of overpayment of a benefit, or existing arrears (rent; Council Tax; water and sewerage; some loans and fines, and child support maintenance).

Up to 25% (originally 40%) of the monthly standard allowance can be deducted, leaving the person with an income below the level assessed to be necessary.

**Sanctions and conditionality:** Over half a million UC sanctions were imposed in the year to October 2022, for failure to meet the claimant commitment or lateness/non-attendance at appointments. An average sanction costs the claimant about £660.

Sanctions can result in claimants not receiving any of their standard allowance for as much as six months. They may receive a hardship payment, which is subsequently repayable.

Evidence on sanctions suggests that they are largely ineffective in supporting people back into work and are often counterproductive.

**Response to the Covid pandemic:** During the pandemic, to support incomes and in particular to help new claimants, UC was increased by £20 per week. There was also a relaxation of some of the rules (almost all new sanctions were suspended from March to July 2020).

The £20 uplift was reversed in October 2021, despite the emerging cost of living crisis.

## **Issues with UC – administration**

**Managed migration:** As claimants are moved from legacy benefits onto UC, there are concerns about: the amplification of existing systemic flaws; adverse changes in benefits for some claimants despite no change in circumstances; the limited transitional protection and unclear entitlement (including limited protection for recipients of severe disability premium); claimants falling into rent arrears; and the risk of payments being stopped as there is no automatic transfer to UC.

**Digital by default:** Claims for UC are made and maintained online. Alternative, offline, options are available but only in exceptional circumstances.

A significant minority of people do not have the internet access or digital skills required to make and maintain their claims online, including many disabled people, people with poor literacy skills and those in rural internet black spots.

**Support for claimants:** Current systems are inadequate for those with complex needs, usually including disability.

There is a lack of intensive casework support available; benefits are sometimes terminated without adequate information; and people may need to engage with multiple agencies to align welfare, health and care needs.

**Administrative errors:** Errors made by DWP and from incorrect advice are common and often cause financial and emotional distress.

These include: over/under payments by DWP; inaccurate calculation of housing costs or payments arriving without the housing element; people being incorrectly required to undergo a new WCA; people on Severe Disability Premium being inappropriately moved to UC; and errors in advice on whether to claim UC.

# Appendix 3:

## List of Judicial Reviews since 2017

### relating to areas within scope of the special inquiry

#### September 2017

[\*Davey, R \(on the application of\) v Oxfordshire County Council & Ors \[2017\] EWCA Civ 1308 \(01 September 2017\) \(bailii.org\)\*](#)

Court of Appeal clarified that the wellbeing principle in the Care Act is complied with if Local authority can demonstrate that it had considered individual's wellbeing. The decision confirmed a significant cut to Luke Davey's care package.

#### December 2017

[\*RF v Secretary of State for Work And Pensions \[2017\] EWHC 3375 \(Admin\) \(21 December 2017\) \(bailii.org\)\*](#)

High Court finds 2017 Personal Independence Payment (PIP) Regulations restricting eligibility for the mobility component for people who experience psychological distress unlawful.

#### November 2019

[\*RR \(Appellant\) v Secretary of State for Work and Pensions \[2019\] UKSC 52\*](#)

The supreme court has ruled against the UK government's attempts to force the bedroom tax on 155 partners of people with severe disabilities,

in a decision that will hamper ministerial attempts to water down human rights legislation.

## June 2020

[\*R \(Johnson, Woods, Barrett & Stewart\) v SSWP\* \[2019\] EWHC23 \(Admin\); \*SSWP v Johnson, Woods, Barrett & Stewart\* \[2020\] EWCA Civ788](#)

A successful challenge to the rigidity of the monthly assessment period regime under universal credit (UC) and the way that earned income is calculated for certain claimants. Implementing regulations came into force on 16 November 2020. [View the regulations.](#) The adjustment or ‘fix’ provided for by these regulations initially operated manually but, as of August 2021, it now operates automatically.

## January 2020

[\*\(TP, AR & SXC\) v Secretary of State for Work and Pensions\* \[2020\] EWCA Civ 37](#)

The Court of Appeal upholding the findings of both High Court judges to the effect that the Universal Credit transitional provisions constitute discrimination under ECHR, art 14 (read with A1P1) in respect of “severely disabled persons” i.e. people who had previously been entitled to receive the Severe Disability Premium in Legacy Benefits.

## January 2020

[\*R \(TD & Ors\) v Secretary of State for Work and Pensions\* \[2020\] EWCA Civ 618; \*R \(TD & Ors\) v Secretary of State for Work and Pensions\* \[2019\] EWHC 462 \(Admin\)](#)

The Court of Appeal found that legacy benefits claimants who had to claim UC after wrong decisions that they are fit to work were discriminated against. Those claimants lost transitional protection and income even after decisions wrongly finding them fit for work were overturned.

## July 2020

[Connor, R \(On the Application Of\) v The Secretary of State for Work And Pensions \[2020\] EWHC 1999 \(Admin\) \(24 July 2020\)](#)

High Court rules mandatory reconsideration requirement for ESA appeals unlawful.

## July 2020

[No: \[2020\] NIQB 53](#)

High Court holds that special rules for terminal illness, in case where claimant cannot demonstrate their death can be reasonably expected within six months, are 'discriminatory' and 'manifestly without reasonable foundation'.

This decision was overturned by the Northern Ireland Court of Appeal, but led to [Westminster Government's commitment to change terminal illness rules](#).

## July 2021

[R \(on the application of Katherine Rowley\) -v- Minister for the Cabinet Office \[2021\] EWHC 2108 \(Admin\)](#)

Failure to provide BSL Interpreters for Data Briefings was Unlawful Discrimination.

## November 2020

[\*R \(Kausar and JL\) v Secretary of State for Work and Pensions CO/987/2020\*](#)

High Court finds DWP unlawfully refused UC to disabled students for 7 years, [only for Secretary of State to change the law to bar them again.](#)

## December 2020

[\*SH, R \(On the Application Of\) v Norfolk County Council & Anor \[2020\] EWHC 3436 \(Admin\)\*](#)

The High Court found changes to local authority charging for care policies to be discriminatory against Disabled people with high support needs.

## March 2021

Errol Graham: Family of man who starved to death after benefits cut off lose High Court challenge against the DWP. No judgment available but see: <https://www.disabilityrightsuk.org/news/2021/march/errol-graham-family-man-who-starved-death-after-benefits-cut-lose-high-court>

## July 2021

DWP to stop 'cold-calling' disabled people to make low benefit 'offers'. [DWP amended its policies and guidance before the JR was heard.](#)

## July 2021

DWP concede new 'transitional protection' for disabled people left financially worse off on transfer to UC. No judgment available but see:

<https://www.gcnchambers.co.uk/dwp-concede-new-transitional-protection-judicial-review-deadman-and-ryan-v-secretary-of-state-for-work-and-pensions-co-1146-2021-22-july-2021/>

## July 2021

Severely disabled man challenged stop to his PIP after 28 days in hospital. No outcome yet.

<https://www.leighday.co.uk/latest-updates/news/2021-news/severely-disabled-man-challenges-halt-to-personal-independence-benefit-payments-after-28-days-in-hospital/>

## January 2022

[\*R\(Binder & Others\) v Secretary of State for Work and Pensions\* \[2022\] EWHC 105 \(Admin\)](#)

High Court judgment declaring that the National Disability Strategy is unlawful following a failure to lawfully consult disabled people and others.

## February 2022

[\*T & Ors, R \(On the Application Of\) v Secretary of State for Work And Pensions\*, \[2022\] EWHC 351 \(Admin\)](#)

High Court dismissed the claim of legacy benefits claimants that Failure to extend £20 per week COVID uplift to claimants of legacy benefits in line with UC constituted discrimination. The court found that difference in treatment was justified.

## February 2022

Severely disabled man receives permission to judicially review hospital-stay benefits rule but faces losing his Motability car lifeline.

<https://www.leighday.co.uk/news/news/2022-news/severely-disabled-man-receives-permission-to-judicially-review-hospital-stay-benefits-rule-but-faces-losing-his-motability-car-lifeline/>

## September 2022

Permission to seek Judicial review relating to Disability Related Expenses disregard refused.

<https://www.judiciary.uk/judgments/rw-v-royal-borough-of-windsor-and- Maidenhead/>

June 2023 *RW v Royal Borough of Windsor and Maidenhead* [2023] EWHC 1449 (Admin) (same case)

[High Court rules autistic man's social and life skills activities must be classed as Disability Related Expenditure](#) when calculating social care charges.

## October 2022

Legal challenge for the promised appeal process in Care Act 2014 to be put in place (9 years after its implementation this still hasn't been done). April 2023 the case was lost so there is still no appeals process for social care provision.

<https://caselaw.nationalarchives.gov.uk/ewhc/admin/2023/866>

## February 2023

Second inquest into the death of benefit victim Jodey Whiting granted.

<https://www.leighday.co.uk/news/news/2023-news/court-of-appeal-grants-second-inquest-into-death-of-jodey-whiting/>

## March 2023

Dr Osman, a blind man, aged 43, of Croydon, was left facing a council tax bill of hundreds of pounds when in the years before 2022 he had been exempt from the charge.

<https://www.leighday.co.uk/news/news/2023-news/croydon-borough-council-ordered-to-pay-blind-self-employed-dr-yusuf-ali-osman-500-damages-over-2022-council-tax-reduction-scheme/>

## July 2023

Appeal hearing regarding *R(Binder&Others)v Secretary of State for Work and Pensions* regarding National Disability Strategy.

The National Disability Strategy published in July 2021, is a cross-government strategy to improve the lives of disabled people. In January 2022, the High Court ruled the strategy unlawful, based on a case brought by four disabled people in relation to the consultation process. The Government paused some parts of the strategy while they appealed the ruling. In July 2023 the Court of Appeal ruled the High Court was wrong to find that the strategy was unlawful.

<https://caselaw.nationalarchives.gov.uk/ewca/civ/2023/810>

## July 2023

High Court finds Government made secret political decision not to implement Grenfell Inquiry recommendations on personal emergency evacuation plans ('PEEPs') for disabled people, but refuses application for judicial review. (Full details of outcome cannot be shared at the moment due to on-going legal work on this.)

[PEEPs press briefing on handout FINAL-JXK2023071411012858.pdf](#)

## July 2023

Helen Timpson's successful legal challenge against 3<sup>rd</sup> party deductions not involving the claimant. These are money which DWP deduct from someone's social security payments to cover debts to energy and water companies. Often the amount taken left people in dire poverty.

<https://caselaw.nationalarchives.gov.uk/ewca/civ/2023/656>

## July 2023

Two disabled rail users have launched a legal challenge to the rail industry's consultation on planned closure of hundreds of rail ticket offices across England over the next three years. (case still to be heard).

# Government backdowns before court hearings

## March 2021

The government has been forced to make a series of promises aimed at improving the accessibility of the way it communicates with those shielding from coronavirus.

The Department of Health and Social Care (DHSC) made the concessions hours before it was due to face a judicial review hearing brought by disabled campaigner Sarah Leadbetter

<https://www.disabilitynewsservice.com/government-backs-down-over-inaccessible-shielding-letters-hours-before-court-case/>

## July 2021

The Department for Work and Pensions (DWP) has agreed to stop intimidating disabled claimants into accepting lower benefit payments than they are entitled to, hours before it was due to face a high court hearing over its tactics.

<https://www.disabilitynewsservice.com/dwp-agrees-to-stop-high-pressure-tactics-on-eve-of-court-hearing/>

# Appendix 4:

## Local Government and Social Care Ombudsman's latest annual review of complaints – England

The Local Government and Social Care Ombudsman published its Annual Report and Accounts 2021-22, which details the success of its work to give more complainants a quicker decision on their case.

Last year (1 April 2021 – 31 March 2022), the Ombudsman focused its efforts particularly on improving waiting times at the early part of its investigation process.

The Ombudsman concentrated on working through cases to reduce its backlog, leading to it significantly increasing the amount of initial investigations it made within 20 working days. Initial investigations are when the Ombudsman decides whether it can and should investigate someone's complaint in more detail.

The Ombudsman also launched its three-yearly policy vision on how its legislative role might develop and change to help remedy injustice for people currently unable to access redress

In the most recent annual report for 2022/23 the Ombudsman's stats show the stark reality of life in England in 2023

The Ombudsman's annual complaints statistics once again back up the harsh realities many people face in key areas of their lives – how their children are educated, how elderly relatives are cared for, and the houses they call home.

Now in its tenth year, the Local Government and Social Care Ombudsman’s annual review of complaints offers a unique insight into the health of local government services in England.

Through the lens of escalated complaints, the report details the common issues seen over the past 12 months, with key areas of concern including Special Educational Needs and Disabilities provision for children and young people, Adult Care Services, and Housing.

In the Ombudsman’s first report in 2014, Education and Children’s Services complaints made up just 17% of the complaints the Ombudsman received. This ever-growing area now makes up nearly a quarter (24%) of the organisation’s workload, and sees the average uphold rate of complaints investigated tipping 84%.

The area making the largest proportion of its complaints about children and education is the South East, with 33% being about this crucial area of work, compared with nearby London in which it makes up just 12% of residents’ complaints.

In the London area, housing and homelessness make up the biggest area of concern (26%), compared with just 15% of complaints nationwide.

In the North residents are more concerned about Adult Care Services, making up nearly a fifth (19%) of complaints, compared with a national average of 13%.

% of complaints upheld each year:

2015/16	65%
2016/17	54%
2017/18	57%
2018/19	58%
2019/20	69%
2021/22	72%
2022/23	84%

## Recent cases:

What follows is a selection of the most recent complaints investigated and upheld by the Ombudsman. Some complaints were not upheld, while others were upheld but the Council had agreed to take action to a suitable remedy so there was nothing further that the ombudsman could achieve by investigating these complaints and they are not mentioned in this document.

## Social Care Charging

### Statement issued by Ombudsman October 2022

The cost of providing care has become an increasingly common theme in the complaints made to the Local Government and Social Care Ombudsman over the past year.

Highlighted in its Annual Review of Adult Social Care the Ombudsman said it is seeing more cases where councils are failing to provide care, or are limiting care, while using cost as the justification.

In one case, a family went from paying nothing for their elderly mother's care to more than £3,500 a month after the council changed the way it assessed people's contributions towards their care because of 'budgetary pressures'. In another case, a young adult's care and support needs were not met while two councils argued about who should foot the bill.

Michael King, Local Government and Social Care Ombudsman, said:

"The issues we are investigating are neither new nor surprising, but do indicate a system with a growing disconnect between the care to which people are entitled, and the ability of councils to meet those needs.

"Care assessments, care planning and charging for care have been key features of our cases this year and a common theme is councils failing to provide care, or limiting it, and justifying this because of the cost. We

appreciate budgets are becoming increasingly stretched but authorities' duties under the Care Act remain and we will continue to hold authorities to account for what they should be doing rather than what they can afford to do."

## Assessment and Care Planning

**October 2022** [Leicestershire County Council](#) has agreed to Ombudsman recommendations to improve how it prepares social care and support plans after a severely visually impaired woman was left without the day-to-day support she needed for 21 months.

The woman looked after herself without support for a significant period, which left her at risk of burning herself when cooking, and falling. She was also not provided with support to access the community and do her shopping, which increased the isolation she felt.

**December 2022** [Bradford council](#)'s failure to provide support to an autistic man has put his employment, family life and sense of self at risk, the Local Government and Social Care Ombudsman has found.

The man, who lives with his partner and children in the city, needs support to go about his daily life, including working to provide for his family.

He complained to the Ombudsman that City of Bradford infringed his human rights by taking four months to complete an assessment of his care and support needs and a further 16 months to provide the services he needed.

When those services were provided – at just four and a half hours per week, some three and a half hours less than recommended by the social worker's assessment – they were not enough, and his partner had to provide additional support.

## Direct Payments

**June 2022** A Worcestershire woman who had had a stroke was left without appropriate care for 12 months because [Worcestershire county council](#) took too long to set up her direct payments.

The situation came about after the council referred the woman to Penderels, a company acting on behalf of the council, to help her recruit a personal assistant. However, case notes suggest the woman struggled to fill out financial forms because of her disability. The woman's social care assessment was finalised in August 2021, setting out the support she needed, but the woman said this was incorrect.

A direct payment agreement was sent to the woman to sign, but she could not do so because of her disability. She was eventually helped to sign, but the council further delayed setting up the payments.

The direct payments had not been set up by the time the Ombudsman started investigating in January 2022.

The Ombudsman found the council at fault for taking too long to complete the woman's social care assessment and her care and support plan, and it failed to put in place her direct payments in a timely fashion.

## Disabled Facilities Grant

**November 2022** A disabled Slough woman has been forced to sleep, eat and wash in her downstairs living room because the council took too long to decide whether she can have a stairlift.

The Local Government and Social Care Ombudsman heard that the woman, who relies on care workers for personal care, has been unable to access her bedroom and bathroom unaided.

The woman applied for a disabled facilities grant (DFG) to install a stairlift to allow her to access her upstairs in May 2021. It took almost a year for [Slough Borough Council](#) to approve instead of the maximum of six months statutory guidance says it should take.

The Ombudsman's investigation into the woman's complaint found the council operated a points-based waiting list for adaptations, which was at odds with statutory guidance.

## Residential and Respite Care

**September 2022** The Local Government and Social Care Ombudsman is cautioning councils against allowing the care homes they work with to have subsidiary contracts with clients following a complaint about [Leeds City Council](#).

The warning comes after it became clear the council had allowed Indigo Care Services Ltd to have a second contract with a woman it had placed in the provider's Paisley Lodge home.

The woman's family complained to the Ombudsman about a number of issues. These included their mother looking unkempt during one visit, items of clothing and other possessions going missing, and only being allowed 'window visits' at certain times during the COVID-19 pandemic.

The family also said the payment and funding arrangements were confusing. The Ombudsman's investigation found that, between June and November 2020, the care home had a second contract in place with the family to make up the difference between what it charged the council for the woman's care, and its private rate. This was contrary to statutory guidance.

The Ombudsman upheld the family's complaints about the care home's delay in registering the mother with a GP, and about her standard of appearance and missing possessions. It did not uphold the complaint about visiting arrangements during the pandemic.

**October 2022 Birmingham City Council** will repay a city family more than 11 years of care home fees after the Local Government and Social Care Ombudsman found the family should never have been charged.

The Ombudsman was asked to step in after the family complained to the council that they were asked to pay a so-called 'top-up' fee for their mother's care after she was moved to a care home in March 2011.

The council could provide no evidence it had offered the family a care home which did not require them to pay the top-up, in accordance with the Care Act. It was not until 2019 that the family discovered this should have been the case after which they made their complaint to the council.

**December 2022 Redcar and Cleveland Council** failed to provide respite care for the family of a boy with complex special educational needs which include Autism, the Local Government and Social Care Ombudsman has found.

The mother of the boy, who herself has Autism and other medical conditions, complained that the council failed to provide the respite care it agreed they were entitled to, even when she was in hospital.

The boy had three-to-one overnight care until April 2020, when his provider ended its package following an incident with the boy. In July that year the council agreed to increase the amount of overnight provision to 74 nights per year, via a different specialist service. However, the provider suspended its service the same month because of COVID-19 restrictions.

The only alternative the council could offer was a provider that would care for the boy in the family home, but the mother had concerns about the level of care and support it could offer.

At one point, the mother had to go into hospital for surgery, and the council failed to provide any respite when she was discharged. Shortly after, the mother was injured by the child and had to return to hospital.

**December 2022** The Local Government and Social Care Ombudsman has criticised [London Borough of Croydon](#) for failing to provide respite care for the mother of a disabled teenager because it would cost too much.

The council argued that the care for the teen, who has Autism, Attention Deficit Hyperactivity Disorder (ADHD) and is largely non-verbal, would cost significantly more than the average placement. This was despite the council not assessing the teenager's specific needs properly or taking into account he might need more than one-to-one care.

The teenager, who can display a range of increasingly challenging behaviours, needs skilled carers who understand how to meet his specific needs. Until he was 16, he attended a residential school as a day pupil, which also offered weekly overnight respite care.

The school stopped providing respite care in December 2019. The council made enquiries with other providers but none could meet the teenager's needs. When the mother found a provider that could offer the support her son needed, the council would not agree, saying it cost too much. She could only pay for limited respite care by cutting back on other care her son needed. So, for three years the teenager had insufficient or no respite care.

**April 2023** A [Leicester care provider](#) who threatened a vulnerable elderly woman with bailiffs because she complained about the care her husband received, has been heavily criticised by the Local Government and Social Care Ombudsman.

The owner of Pine View Care Homes Ltd initially responded to the family's complaint suggesting they were only complaining to get out of paying for outstanding fees.

The response said: *"families like yours disgust me, as soon as there is an invoice to pay, all the complaints come out, no complaints were made when [Mr C] was a resident but as soon as he leaves and I ask for the invoices to be paid, this is what we get. Disgusting."*

The response said the family had seven days to pay the debt and added: *“If this is not paid the debt will be sent to our debt collectors to collect what is legally owed. We are not gangsters...”*

## Safeguarding

**November 2022** [Birmingham City Council](#) A Birmingham man has been left in unsuitable temporary accommodation for eight years despite the city council knowing it did not meet his needs as a wheelchair user, the Local Government and Social Care Ombudsman has found.

For the past eight years, the man has been unable to access the property without the help of others because it has a step up. He said he has fallen while trying to get inside the property, and his wife has had to drag him inside, including when she was pregnant.

**January 2023** Councils need to ensure any care visits they arrange give enough time for care workers to do their job properly the Local Government and Social Care Ombudsman has said.

The warning comes after [Warrington Borough Council](#) was found to have allocated 15-minute care calls to more than 300 people in the region, despite national guidance stressing these were ‘not usually appropriate’.

In one case, which led to the Ombudsman’s wider investigation, care workers had sometimes stayed for just three minutes, despite the family paying for the full visit.

## Special Educational Needs

**April 2022** [Cambridgeshire County Council](#) has refused to apologise to a family after it left their clinically vulnerable son without any education or support during the COVID-19 crisis.

The nine-year-old, who has complex Special Educational Needs including severe neuro-disabilities and speech and language delay, could not attend his school throughout the pandemic on the advice of his GP. He has had no formal schooling since September 2020 and has only in the last month been provided with some education at home.

The council issued the boy's Education, Health and Care (EHC) Plan in 2016, and last amended it in 2018. It should have reviewed this annually but has failed to do so. This means the boy's plan does not reflect his current needs and the support he requires to meet them.

Despite the Local Government and Social Care Ombudsman investigating the complaint and finding the council at fault, Cambridgeshire has so far refused to agree to any of the Ombudsman's recommendations to put things right for the family.

**December 2022** [Oxfordshire County Council](#) has been told it needs to pay £5,000 to the mother of an Autistic boy to make up for the 12 months education he missed when he was unable to attend school.

The mother asked the Ombudsman to investigate after her autistic son was left without education when he became too anxious to attend his primary school. She said the lack of proper education has had a significant impact on her daily life and employment.

# Annex A:

## Progress against 2016 inquiry recommendations

### Recommendations

114. The Committee recommends that the State party:

(a) Conduct a cumulative impact assessment of the measures adopted since 2010, which are referred to in the present report, on the rights to independent living and to be included in the community, to social protection and to employment of persons with disabilities. The State party should ensure that such an assessment is rights-based and meaningfully involves persons with disabilities and their representative organizations;

#### Westminster:

WeG continues to refuse to carry out a cumulative impact assessment.

The EHRC made a number of recommendations in its 2015 report, *Future fair financial decision-making*, for WeG's approach to future Spending Reviews (and tax and spending decisions more broadly). A key focus of those recommendations was that HM Treasury should extend its analysis of

the aggregate distributional impacts of tax and spending decisions to analyse the aggregate impact of decisions on people sharing different protected characteristics – that is, carry out a CIA.

HM Treasury has never fulfilled this recommendation.

In place of this, [EHRC commissioned their own CIA](#). They found that negative impacts are particularly large for households with more disabled members, and individuals with more severe disabilities, as well as for lone parents on low incomes.

EHRC also commissioned [a cumulative impact on living standards of public spending changes](#). Key findings included that: overall public spending per head is forecast to fall by around 18% (just over £900) in England between 2010/11 and 2021/22, 5.5% (just under £300) in Wales and just over 1% (around £100) in Scotland. By 2021/22, overall spending per head will be 36% higher in Scotland than in England and 17% higher in Wales than in England; the differences between the countries are particularly acute for households with lower incomes. Cash losses for lower deciles are larger in England than Wales or Scotland due to the overall scale of cuts in spending being far greater in England.

DDPOs have not been invited by WeG to participate in discussions about the cumulative impact of the measures covered by the report including our lived experience.

### **Northern Ireland:**

The Secretary of State and NIO failed to undertake appropriate screening of the cumulative impacts of the proposed 2023-24 Northern Ireland Budget, contrary to it's own Equality Scheme, and contrary to Section 75 and Schedule 9 of the Northern Ireland Act 1998.

## Scotland:

Government, in all its forms (including local authorities), still does not take account of the interlinking barriers that disabled people face and the cumulative impact of these. In addition, their focus on working in silos is a major barrier to addressing the complex and multi-faceted barriers and makes the landscape very difficult for disabled people and DPOs to navigate.

DDPOs acknowledge the Scottish Government's efforts to impact assess its policies including producing a qualitative impact assessment of budget decisions against all protected characteristics. However, we are not aware of how the Scottish Government assesses the cumulative impact of different policies on disabled people.

Disability competence in policy and practice is persistently lacking at Scottish Government, NHS and local authority levels – “they don't know what they don't know” and the profound impact of the financial climate for disabled people means that there is no time for them to stand back and learn. Repeated evidence tells us disabled fare worst in every area of life and have been hit especially hard by the pandemic and cost of living crisis. Yet repeated policies fail to address the poverty and inequality faced.

## Wales:

**(b) Ensure that any intended measure of the welfare reform is rights-based, upholds the human rights model of disability and does not disproportionately and/or adversely affect the rights of persons with**

disabilities to independent living, to an adequate standard of living and to employment. To prevent adverse consequences, the State party should carry out human rights-based cumulative impact assessments of the whole range of intended measures that would have an impact on the rights of persons with disabilities;

### Westminster:

WeG says it follows the social model/human rights model of disability but this claim is not substantiated by their policies.

WeG makes no attempt to measure unmet needs among DDP with respect to article 19 or article 28 rights. They delegate responsibility for meeting need to LAs and local JobCentres without mechanisms for monitoring how well they do this and without listening to feedback from robust research, professional opinion or lived experience regarding the existence of high levels of unmet need.

WeG claims that promoting employment and the idea that everyone can work is consistent with a social model/human rights model approach to disability in that it looks at what we “can do”, not what we “can’t do”. Policies for incentivising DDP into employment focus on removing essential daily living income and support as a way of coercing behaviour change (for example the cut to benefits for claimants in the EWA WRAG or exposing claimants to conditionality and sanctions). This represents a denial of human rights when the reality for many is that behaviour change is not possible for reasons of disablement. As the [DWP’s own evaluation shows](#), it pushes DDP to leave the benefits system into a condition of no salaried income at double the rate than would ordinarily happen.

More opportunities would open up if instead DDP were given the self-identified support we need. This would require additional investment,

especially since disability prevalence is rising. However, it would not be an investment without a return. Figures from [Independent Living Fund Scotland show that its £6.85 million allocation to Northern Ireland recipients in 2019](#) generated a social value of £1: £10.89. This is based on a Total Present Value of £74,569,097 created against the input of £6,850,000.

The choice to deny disability and remove support is political. It is not social model and not a human rights model. The model that best fits WeG's approach and which underpinned the development of the welfare reform programme is the [scientifically discredited Waddell Aylward biopsychosocial model of disability](#).

### **Northern Ireland:**

No action has been taken in Northern Ireland. The State should consider learning from the Scottish approach.

### **Scotland:**

As noted above, we are not aware of how or if the Scottish Government meaningfully assesses the cumulative impact of different policies on the rights of disabled people. Nor how the impact of different policies is measured across the life course.

There is a lack of understanding of the cumulative and interrelated barriers that disabled people face. In our view, in Scotland at present there is a tendency to focus on specific issues without considering how this interacts with other matters and how the lack of intersectional focus

fundamentally impacts the barriers disabled people face. For example, the Scottish Government's focus on child poverty has had the unintended consequence of diverting money away from tackling disabled people's poverty, despite the fact that 43% of children living in poverty live in a household with at least one disabled member.

### **Wales:**

**(c) Ensure that any intended legislation and/or policy measure respects the core elements of the rights analysed in the present report, that persons with disabilities retain their autonomy, choice and control over their place of residence and with whom they live, that they receive appropriate and individualized support, including through personal assistance, and have access to community-based services on an equal basis with others, that they have access to security social schemes that ensure income protection, including in relation to the extra cost of disability, compatible with an adequate standard of living and ensure their full inclusion and participation in society, and that they have access to and are supported in gaining employment in the open labour market on an equal basis with others;**

### **Westminster:**

The right of DDP to live in the community has been dramatically eroded over successive years of cuts since 2010. As predicted by DDP, the closure of the Independent Living Fund in 2015 did not represent a mere transfer

of support provision from the ILF to LAs [but led to real and substantial cuts to support for severely disabled people living in the community](#).

The constant drive by LAs to make year on year savings has led to a range of practices for cutting support to live in the community that are non-transparent, unlawful and unethical. The percentage of cases upheld by the [Local Government and Social Care Ombudsman \(LGSCO\)](#) has shown a [relentless rise over the last decade](#). The faults the Ombudsman finds in its investigations are often not due to one-off staff errors, but are increasingly caused by the measures employed by councils and care providers to mitigate the squeeze on their resources. At least one LA targeted cuts on DDP living in their own homes receiving Personal Assistance and [contracted an outsourced provider who – according to a whistleblower – offered bonuses for cuts](#).

The right of DDP to live in the community is under constant threat from cuts and attempts to set blanket policies capping costs for community support with the alternative being residential care against the disabled person's wishes.

In 2018, [the EHRC threatened to judicially review 13 Clinical Commissioning Groups over concerns about their blanket NHS Continuing Healthcare policies](#), which placed arbitrary caps on funding and failed to consider the specific needs of individual disabled people. A number of LAs have also passed policies which make assumptions that DDP “are placed in cheaper accommodation settings where appropriate”. Examples include [Barnet](#), [Bristol and Devon](#).

DDP living in the community with unmet support needs have unequal life chances, being unable to do things that non-disabled people take for granted such as washing everyday, being able to leave the house, having

fresh cooked meals, having a clean home and choosing what time they go to bed.

Overnight support in your own home is now virtually unheard of and support with domestic tasks such as cleaning and shopping are difficult to access. One LA was recently criticised by the [Ombudsman for commissioning 15-minute social care support visits, not allowing staff to do their jobs properly](#).

WeG has been unable to meet its targets for de-institutionalisation due to the lack of appropriate community-based support.

DDP are calling on WeG to radically and fundamentally overhaul the social care support system in co-production with DDPOs. WeG have continued to ignore requests to meet with DDPOs to look at proposals for [a new national independent living support service that DDP across England have worked together to draw up](#).

Levels of benefits in the UK are inadequate and are way below what is calculated as the minimum income standard. WeG policies are targeted at moving DDP off disability benefit tops ups onto standard allowances. The standard allowance of Universal Credit is deliberately only enough to sustain a temporary period of unemployment. It is an inappropriate level for people who face barriers to work. Proposals in the [new health and disability white paper](#) will push hundreds of thousands of disabled people who do not qualify for PIP onto nothing more than the UC standard allowance.

WeG encourages DDP to earn their way out of poverty while not doing enough to tackle the material barriers that we face to employment and to ensure that DDP are not pushed into unsuitable work that is harmful for their physical and mental health.

**Northern Ireland:**

No action has been taken in NI.

**Scotland:**

Issues addressed under other headings.

**Wales:**

**(d) Ensure that public budgets take into account the rights of persons with disabilities, that sufficient budget allocations are made available to cover the extra costs associated with living with a disability and that appropriate mitigation measures, with appropriate budget allocations, are in place for persons with disabilities affected by austerity measures;**

**Westminster:**

Policy is set according to overriding economic ideology. No attempt is made to calculate budget allocations according to genuine need. The premise that large numbers of benefit applicants are not deserving underpins targets to reduce caseloads and restrict eligibility.

LAs set savings targets and make cuts year on year. WeG claims they cannot be in such financial straits because overall they continue to have large amounts in their reserves. LAs have allegedly been instructed by

WeG to stop issuing section 114 notices (that is, publicly declaring bankruptcy). WeG and LAs maintain that legal duties to meet statutory responsibilities including support for DDP are not breached. DDP's lived experience speaks loudly against this.

### **Northern Ireland:**

No action has been taken in NI.

### **Scotland:**

Other funding issues discussed elsewhere.

There must be more transparency around the Scottish Government budget process. This includes for funding that is allocated at local authority and health board levels, where much of the allocation and expenditure directly impacts the right to independent living.

Glasgow Disability Alliance's 'Budgeting for Equality' 6-month action research project found that disabled people in Scotland want to be involved in how public money is spent but face multiple and complex barriers to their participation.

### **DDPO funding**

DDPOs are representative organisations of Deaf and disabled people. The UNCRPD requires their involvement in implementing and monitoring the Convention. States and public authorities should prioritise disabled people's views, through their DDPOs, and they should support the capacity and empowerment of DDPOs. This means that DDPOs,

representing the collective and must be adequately supported and funded.

At present DDPOs do not get sufficient budgets to cover the extra costs incurred, such as for reasonable adjustments for disabled members, especially at a time when DDPO operational costs are rising steeply due to inflation. Funders also do not take account of the fact that many DDPOs are working holistically across all policy areas because of the magnitude and range of barriers disabled people face and are working with Deaf and disabled people in crisis to support them. Conditionality of some funding programmes includes restrictions on spending on adjustments and minimum income thresholds which exclude DPOs from applying.

### Wales:

**(e) Introduce the adjustments necessary to make all information, communications, administrative and legal procedures in relation to social security entitlements, independent living schemes and employment/unemployment-related support services fully accessible to all persons with disabilities;**

### Westminster:

Although DWP has worked on improving how it communicates with disabled benefit claimants, claimants receive no information about how to make complaints and enforce their rights in any format.

Each LA has different policies and ways of working. Anecdotally we hear that social care users are not made aware of their rights and that information is not accessible. Breaches of the Care Act happen on a daily basis within LAs – for example not providing accessible information in advance of reviews/reassessments and not being clear with social care users whether they are being contacted for a review or for a reassessment and what the process is.

### **Northern Ireland:**

### **Scotland:**

There is a widespread lack of consistency in the making of adjustments to ensure all information, communications, administrative and legal procedures in relation to social security entitlements, independent living schemes and employment/unemployment-related support services is fully accessible to all disabled people. Obtaining accessible information, communications and procedures has been described as a ‘constant battle’.

In relation to the Scottish Government, some DPOs feel that when progress is made with government departments or civil servants this can be lost when specific staff members move on and there is a lack of succession planning and communication around this. Accessible communications needs to be a centralised function within Scottish Government to ensure that it is done consistently and across the board.

### **Welfare rights advice**

Disabled people are not served well by inaccessible advice services and are therefore excluded from vital support and anti-poverty initiatives that could lift them out of poverty. This lack of accessibility is not restricted to lack of accessible information and communication and built environment but also extends to ‘disability competency’ (awareness of the cumulative impact of the barriers disabled people face) that many advice services lack. Disabled people need accessible, targeted welfare rights advice and representation to be able to achieve income maximisation and successful outcomes.

### **Digital inclusion**

The pandemic accelerated moves to online services, and the Scottish Government continues to implement a digital-by-default policy for public services. However, disabled people are still less likely to use the internet, and are excluded from services and support because of lack of technology, connectivity and confidence, and alternatives to digital. There is limited evidence available about the impact of digital by default policies on disabled people.

### **Wales:**

**(f) Ensure access to justice by providing appropriate legal advice and support, including through reasonable and procedural accommodation for persons with disabilities seeking redress and reparation for the alleged violation of their rights, as covered in the present report;**

## **Westminster:**

Access to justice was deliberately barred for areas covered by the special inquiry and has not been restored.

WeG has made no effective remedy for the loss of legal advice and law centres that have been a direct consequence of their changes to legal aid funding rules.

Legal aid for welfare cases has not been reintroduced.

Mandatory reconsideration is still in place for Personal Independence Payment deliberately introduced as an extra hurdle for DDP seeking to overturn wrongful benefit assessment decisions.

Social care users face non-transparent, complex and inaccessible processes to challenge decisions regarding their support awards. Most do not have access to community care lawyers who are now scarce as well as overwhelmed with demand. The appeals process under the Care Act 2014 still has not been introduced. [Judicial reviews have proved themselves inappropriate as a place to challenge individual support decisions.](#)

The Health and Social Care Ombudsman has been dealing with growing numbers of cases but many DDP do not know about this option and do not have the support to go through their LA's complaints procedure as the first step before they can go to the ombudsman.

## **Northern Ireland:**

Limited progress has been made at this point.

## **Scotland:**

There is a lack of support for Deaf and disabled people in the civil and criminal justice system – including barriers to getting advice and adjustments<sup>469, 470</sup> and the increasing use of audio-visual technology and remote trials.<sup>471</sup>

Deaf and Disabled people are more likely to say they have experienced a civil law problem.<sup>472</sup> But there are still barriers to getting advice, for example, lack of availability, inaccessible information and buildings, not being listened to, costs, lack of legal aid and discriminatory attitudes.<sup>473</sup> Costs associated with reasonable adjustments are not met by legal aid.<sup>474</sup> For example, BSL users requiring the use of interpreters when dealing with lawyers.

### **Deaf BSL users**

Adjustments for Deaf people are not readily available in the justice system. Deaf BSL users are still not allowed to serve on juries and there is

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<sup>469</sup> Equality and Human Rights Commission (2020), [Inclusive justice: a system designed for all](#)

<sup>470</sup> Equality and Human Rights Commission (2020), [Inclusive justice: a system designed for all](#)

<sup>471</sup> Equality and Human Rights Commission (2020), [How coronavirus has affected equality and human rights](#)

<sup>472</sup> Scottish Government (2021), [Scottish Crime and Justice survey 2019/20](#)

<sup>473</sup> Inclusion Scotland (2021), Disability discrimination and access to advice survey results (unpublished)

<sup>474</sup> Scottish Government (2020), [Legal Aid Reform in Scotland Consultation – Scottish Government Analysis](#)

a lack of available high-quality BSL/English interpreters in courts and police stations.

### **People with learning disabilities**

There continues to be a dearth of support for people with learning disabilities in the criminal justice system. A significant number of the people with learning disabilities who enter the criminal justice system would not be entitled to support by local authorities due to the increasingly narrow needs assessment criteria of 'critical' and 'substantial' need.

We are concerned that people with learning disabilities are more likely to be diverted into the forensic system, meaning that they are detained for longer periods or subject to greater restrictions.

### **Wales:**

**(g) Actively consult and engage with persons with disabilities through their representative organizations and give due consideration to their views in the design, implementation, monitoring and evaluation of any legislation, policy or programme related to the rights addressed in the present report;**

### **Westminster:**

DDPOs are now more frequently invited to participate in consultation by DWP and the Disability Unit but our views are disregarded. This is not genuine engagement.

Absence of contact from DHSC and ability to input into legislation and policy relevant to article 19 rights is notable.

Information is deliberately withheld from the public so that the impacts of policies are concealed. We have no role in monitoring or evaluation.

### **Northern Ireland:**

### **Scotland:**

Although the Scottish Government endeavours to consult and engage with disabled people this could be more meaningful with transparency and accountability. There is growing 'consultation fatigue' amongst disabled people who are regularly asked for their views on issues but feel that it rarely leads to any real change in their day-to-day lives. This is another example of the disconnect between rhetoric and reality.

There is inconsistency in the extent to which the Scottish Government actively consults and engages with disabled people and DPOs. For example there was no consultation prior to the decision to remove the requirement for face masks health and social care settings. SILC is concerned that 'due consideration' is not given to the views of disabled people in the Scottish Government's consultation processes. A DPO involving hundreds of disabled people in formulating a consultation response is not given more weighting than a response from an individual. The collective voice of disabled people, and our human rights which the Scottish Government has widely declared support for, must be given more prominence.

## Learning Disability, Autism and Neurodiversity Bill

There is concern that the consultation process for the learning disability bill is not accessible for people with a learning disability. Members of People First (Scotland) do not feel listened to in the process so far and have been unable to sit on the lived experience panel. Members of the panel must be individuals, excluding those from membership organisations being represented on the panel.<sup>475</sup>

There is also concern about the grouping of learning disability, autism and neurodiversity in the same Bill. These are different impairment groups and as such require different approaches and targeted funding. DPOs are concerned should this Bill be passed it will lead, in future, to further combined legislation and work and a subsequent lack of effect focus for individual groups and their experiences. For example, there is now a strategy for all 3 groups. DPOs and other charities have persistently expressed this view to the Scottish Government, however no consideration appears to have been given to these concerns.

## Wales:

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<sup>475</sup> [Who can apply? – Learning Disability, Autism and Neurodiversity Bill – Lived Experience](#)

[Advisory Panel: recruitment information – gov.scot \(www.gov.scot\)](#) – “You will be representing yourself on the panel as an individual expert by experience, rather than representing the views of a specific organisation.”

“If you are an office-bearer (paid or unpaid) or paid staff member of an interest group that has a publicly-stated stance on the Bill or Commissioner, then you will not be able to apply for a role on this panel”

(h) **Take appropriate measures to combat any negative and discriminatory stereotypes or prejudice against persons with disabilities in public and the media, including the assertion that dependency on benefits is in itself a disincentive to seeking employment, implement broad mass media campaigns, in consultation with organizations representing persons with disabilities, particularly those affected by the welfare reform, to promote them as full rights holders, in accordance with the Convention, and adopt measures to address complaints of harassment and hate crime by persons with disabilities, promptly investigate those allegations, hold the perpetrators accountable and provide fair and appropriate compensation to victims;**

**Westminster:**

WeG ministers are themselves responsible for enflaming hostility towards DDP as benefit recipients. Certain sections of the media have picked up on their rhetoric and pushed negative portrayals to a new level: whereas the situation that triggered the special inquiry involved demonising of benefit claimants that led to increased hostility towards and harassment of DDP, it is disability benefits specifically that have been the target of demonisation this year (2023).

Any initiatives aimed at improving hate crime reporting and increasing prosecution rates are welcome. However, in order to tackle this specific issue of negative portrayals leading to increased harassment and hate crime, we need hate crime legislation to extend “stirring up” offences to disability. WeG has avoided this to date.

**Northern Ireland:**

## **Scotland:**

### **Hate crime**

There was a 14% increase in the number of disability hate crime charges between 2019/20 and 2020/21.<sup>476</sup> This is the highest number of charges reported since it came into force in 2010.

Hate incidents which do not have the supporting evidence to meet the threshold for Police Scotland to report to the Crown Office and Procurator Fiscal Service increased significantly during the pandemic.

There is a lack of data on disability hate crime by impairment type.

Police Scotland's operational response to hate incidents and crimes that are reported (e.g. through Third Party Reporting) varies.

DDPOs have seen an increase in neighbour disputes and anti-social behaviours which disabled people feel are motivated by disability prejudice but cannot be reported as crimes.

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<sup>476</sup> [Hate Crime in Scotland, 2021-22 | COPFS](#)

## **Children and young people**

Disabled children experience bullying at school.<sup>477 478</sup> However, Scottish Government does not collate bullying data at a national level<sup>479</sup> and recording in schools is inconsistent.<sup>480</sup>

An investigation by the Children and Young People's Commissioner for Scotland found that restraint and seclusion appear to be used more frequently on disabled children in schools.<sup>481</sup>

## **Wales:**

**(i) Ensure that, in the implementation of legislation, policies and programmes, special attention is paid to persons with disabilities living on a low income or in poverty and to persons with disabilities at higher risk of exclusion, such as persons with intellectual, psychosocial or multiple disabilities and women, children and older persons with disabilities. Those**

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<sup>477</sup> Scottish Parliament Equalities and Human Rights Committee (2017), [It is not Cool to be Cruel: Prejudice-based bullying and harassment of children and young people in schools](#)

<sup>478</sup> Enable Scotland (2017), [#IncludED in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability](#)

<sup>479</sup> Scottish Government (2018), [Recording and monitoring of bullying incidents in schools: supplementary guidance](#)

<sup>480</sup> [Approaches to recording and monitoring incidents of bullying in schools \(education.gov.scot\)](#)

<sup>481</sup> Children and Young People's Commissioner for Scotland (2020), [No Safe Place: Restraint and Seclusion in Scotland's Schools](#)

measures should be put in place within contributive and non-contributive regimes;

### **Westminster:**

The opposite is happening: instead of paying special attention, WeG is seeking to weaken identification of DDP as belonging to the disability protected characteristic so that disproportionate and discriminatory impacts of its policies can be hidden. The more disability within a household, and the more excluded DDP already are, the harder they are hit by WeG legislative and policy measures.

### **Northern Ireland:**

### **Scotland:**

Intersectional discrimination is a major issue and its impact is not always immediately apparent to policy and decision-makers. There is a widespread lack of focus and understanding of intersectional barriers and this is underpinned by a clear lack of intersectional data in Scotland which makes it difficult to set baselines and targets and to monitor outcomes. This includes disabled people generally, but also applies to specific impairment types, in particular for people with a learning disability.<sup>482</sup>

A Scottish Government evidence synthesis found that:

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<sup>482</sup> [The challenges of estimating Scotland's learning disabled population and why it matters | FAI \(fraserofallander.org\)](#)

“Currently in Scotland there is a lack of intersectional data on outcomes, and policymaking rarely takes an intersectional approach” and,

“A "one size fits all" approach to narrowing inequality leaves people behind, especially where multiple inequalities intersect.”<sup>483</sup>

Deaf and Disabled people have been and continue to be left behind exactly because of a failure to recognise and respond to intersecting inequalities and barriers. The complex nature of many Deaf and disabled people’s lives, including that we are impacted by so many services, means that the risk of being left behind is greater and the consequences more severe.

### **Wales:**

**(j) Set up a mechanism and a system of human rights-based indicators to permanently monitor the impact of the different policies and programmes relating to the access to and enjoyment by persons with disabilities of the right to social protection and an adequate standard of living, the right to live independently and to be included in the community and the right to work, in close consultation with persons with disabilities and their representative organizations in all regions and countries that constitute the State party;**

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<sup>483</sup> [Using intersectionality to understand structural inequality in Scotland: evidence synthesis – gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/using-intersectionality-to-understand-structural-inequality-in-scotland-evidence-synthesis-2022/pages/100-to-150.aspx)

### **Westminster:**

There is no mechanism or system that does this. Engagement with DDPOs is limited and does not have a human-rights basis.

[Previous WeG ministers have expressed the view that human rights are not affordable.](#)

We very much welcome that WeG has dropped its Bill of Rights and plans to come out of the European Convention on Human Rights.

### **Northern Ireland:**

### **Scotland:**

The language of human rights is used often by the Scottish Government to set out policy intentions, but that it rarely leads to real change in practice. This implementation gap between policy and reality is regularly identified by DPOs and other services that work directly with disabled people.

A more effective accountability and governance infrastructure for disability equality in Scotland is needed. This includes not only setting up a mechanism and a system of human rights-based indicators to permanently monitor the impact of the different policies and programmes, but also collating and tracking progress on meeting recommendations made via various Scottish Government groups, and action plans. The absence of institutional memory within the current

system and structures is frustrating, and disempowering and can be understood as a mechanism by which systemic discrimination occurs.

The current consultation on a new human rights law for Scotland, which includes incorporating the CRPD into Scots law, provides the opportunity to move from rhetoric to action. DPOs and civil society fully support the introduction of a new human rights law which will ensure the strongest protection possible with accessible routes to justice, as well as the necessary resources and support to effectively implement a culture of human rights in Scotland.

### Wales:

**(k) Respond to the present report within the time limit prescribed under the Optional Protocol, widely disseminate the Committee’s findings and recommendations and provide appropriate follow-up to the recommendations of the present report, including during the consideration of the State party’s initial report before the Committee.**

### Westminster:

WeG has reported back to the Committee on an annual basis since 2016. Reports are not promoted – we have to look for them on the *gov.uk* website to know when they are published – and there is not engagement over their content with DDPOs.

### **Northern Ireland:**

### **Scotland:**

As far as we are aware, the UK government has provided several follow-up reports to the Committee, with the exception of 2019 and 2020 due to the pandemic. We believe that the Scottish Government fed into these reports to cover devolved issues. We are not aware of any further work done to by the Scottish Government to disseminate the Committee's Scotland specific findings and recommendations.

We understand that the Scottish Government took measures to mitigate some of the UK Government's welfare reforms criticised by the Committee. However, given that there has since been further devolution and the Scottish Government is now responsible for disability benefits and a wide range of other areas impacting disabled people, it is important that it takes action on the Inquiry findings and recommendation (K).

### **Wales:**

# Annex B:

## List of Issues

### **Westminster government**

#### **Article 19**

- 1.** What plans does WeG have to address the retrogression, re-institutionalisation and resegregation that has continued to occur since 2016?
- 2.** How does the government justify its continuing failure to ensure that reform of the Mental Health Act 1983 will result in people with psychosocial disabilities and people with intellectual disabilities receiving their full human rights under the UNCRPD, including a total end to involuntary detention in psychiatric hospitals and forced treatment, and what action will the government now take to redress this?
- 3.** How does WeG measure DDP's rights under article 19, what system does it have for monitoring how far the devolved nations and English LAs are meeting the article 19 responsibilities it has delegated to them and what plans does it have to improve those?
- 4.** How does WeG measure the impact of social care charging on DDP?
- 5.** What is WeG doing to address the recruitment crisis in social care including for DDP living in the community and employing their own Personal Assistants while ensuring that vacancies are filled by suitable appointments with the right skills, experience and attitudes?

6. What is WeG doing to ensure that social care staff are trained in and have understanding of social justice issues and practices that centre principles of intersectionality, independent living, social model of disability and human rights.
7. How does engage with WeG over social care support policy and legislation?
8. Access to housing: What steps has WEG taken since 2016 to increase disabled people's access to good quality accessible housing in the community.
9. **(a)** Will WeG ensure that people with psychosocial disabilities and people with intellectual disabilities who have experienced detention under the Mental Health Act 1983 lead the planned national inquiry into neglect and abuse of people made subject to the Act and high death levels among them – and that the inquiry is fully independent?  
  
**(b)** Will WeG also ensure reparations and redress for detained patients who have experienced this horrific neglect and abuse, in line with the CRDP Deinstitutionalisation Guidelines?
10. Will WeG carry out a public inquiry into the barbaric torture, violence, and abuse perpetrated against disabled children and young people in special education provisions / children care homes?
11. Does WeG have any plans to review its reservation and interpretative declaration under article 24?
12. How will WeG carry out a public inquiry into school intake discrimination ensuring that Deaf and Disabled pupils have justice and equal chances to attend mainstream education and are not forced into the

special/residential schooling system due to a lack of resources in the mainstream system?

- 13.** What is WeG doing to address intersectional discrimination within access to education based on disability, social and protected characteristics?
- 14.** What lessons has WeG learned from COVID-19 and what is it putting in place to ensure that DDP will not be disproportionately impacted in future pandemic or other emergency situations?

## **Article 27**

- 1.** What plans does WeG have to evaluate the impact of current labour market trends on the employability of DDP ensuring it takes an intersectional approach to include protected characteristics and social issues to avoid homogenising Disability?
- 2.** What is WeG doing to improve the operational capacity of the Access to Work scheme and remove the barriers it currently creates towards employment for DDP?
- 3.** What evaluation has WeG undertaken of the impact of in-work progression on DDP and what mitigations does it plan to put in place?
- 4.** What plans does WeG have with respect to disability pay gap reporting and will this take an intersectional approach?
- 5.** What protections will WeG put in place to ensure that Deaf and Disabled claimants are not pushed into unsuitable employment and what work is WeG doing with employers to ensure that work works enough for a decent standard of living and to tackle disability discrimination within the workplace?

6. What is WeG doing to challenge hostility towards requests for reasonable adjustments by Deaf and Disabled workers from employers and from colleagues within the workplace?
7. What plans does WeG have to study health data and ensure that social security and labour market policies are based on an accurate measure of the limitations towards employment that the Deaf and Disabled population face?

## **Article 28**

1. What is WeG doing to evaluate the impact of joint household social security claims under Universal credit on all Deaf and Disabled women?
2. What is WeG's reasoning for maintaining inequality within hate crime law whereby stirring up offences are not extended to disability and intersects between disability and other protected characteristics?
3. What is WeG doing to positively portray benefit claimants:
  - a. Within the media?
  - b. Among the general public?
  - c. Within political discourse?
4. What plans does WeG have to carry out a cumulative impact assessment into tax and welfare reform changes since 2010 that assesses not just financial losses but also impact on health and well-being?
5. Will WeG commission an independent inquiry into benefit deaths, how does it view its safeguarding duty towards Deaf and Disabled claimants and what is it doing to discharge its safeguarding duty?
6. What plans does WeG have to ensure benefits rates are adequate in meeting: a) the extra costs of disability; b) the costs of long-term

unemployment faced by Deaf and disabled people unable to earn a decent income through paid work?

- 7.** Why will WeG not consider automatic enrollment on to Universal Credit for Deaf and Disabled claimants and what protections does it have in place particularly for claimants who face barriers to literacy and communication and who are digitally excluded?
- 8.** What is WeG doing to address poverty among Deaf and Disabled people and what further measures are planned to support them through the cost of living crisis?
- 9.** How does WeG ensure that Deaf and Disabled benefit claimants understand their rights under the Equality Act 2010 and that work coaches comply with their duties to make reasonable adjustments?
- 10.** What has been done to improve access to British Sign Language and other communication support both in person and using remote technology as best meets the access needs of the individual claimant?
- 11.** How does WeG centrally record the communication and support needs and reasonable adjustments required by benefit claimants across all caseloads and use that data to make high level strategy decisions relating to legislative and policy decisions relevant to article 28?
- 12.** How plans does WeG have to improve data collection with regards to DDP on Universal Credit who are not within either the LCW or LCWRA groups? Why does it continue not to publish sanctions data that is disaggregated according to disability and what is it doing to address this?
- 13.** What plans does WeG have to improve transparency and access to disability-related information held by DWP?

14. What plans does WeG have not just to meet with DDPOs, but to address and to engage with DDPOs and act on their concerns regarding the white paper (*Transforming Support: the health and disability white paper*)?

### **General:**

1. How will WeG improve access to justice for DDP with respect to defending their rights under articles 19, 27 and 28?
2. How does WeG ensure that DDP are able to express their views and defend their interests without criminalisation?
3. What plans does WeG have to improve the capacity of DDPOs and to ensure that DDPOs are adequately resourced to undertake activities under the Convention on the Rights of Disabled People?
4. How will WeG ensure the independence of engagement networks and of the Equality and Human Rights Commission?

### **Regarding the situation for DDP in Northern Ireland:**

1. What action will the Westminster Government take as co-guarantors of the Good Friday Agreement to ensure that the political institutions are re-established on a sustainable footing to ensure that there are mechanisms in place to advance legislation in Northern Ireland?
2. What actions will the Westminster Government take to ensure that the state in Northern Ireland has access to appropriate resources to deliver public services?
3. What actions will the Westminster Government take to progress their commitment to legislate for a Bill of Rights for Northern Ireland?

## Northern Ireland

### Article 19

1. What action will the State in NI take to advance the reform of Adult Social Care ensuring that that the right to independent living is protected in legislation and that funding is made available to advance improvements co-designed with disabled people?
2. In the absence of sustainable government in NI- what actions will be taken to protect investment in social care?
3. What steps will be taken to ensure that the Independent Living Fund is reopened?
4. What steps will be taken to ensure that financial decisions taken in Northern Ireland are compliant with Section 75?
5. What measures will the State in Northern Ireland take to ensure that the state in Northern Ireland incorporates the UNCRPD into law?
6. What actions will be taken by the State in Northern Ireland to ensure that adult safe guarding legislation is developed in partnership with disabled people and disabled people's organisations to ensure that all interventions are based on informed consent?
7. What measures will be taken by the State in Northern Ireland to ensure that disabled people have access to justice in cases of alleged abuse?
8. What measures will the state in Northern Ireland take to ensure that disabled people have access to emergency refuges on an equal basis with others?

9. What actions will be State take to ensure that the current political crisis does not adversely impact on disabled people through the reduction in the building of accessible social homes, reductions in housing support and housing adaptations?
10. What measures will the State take to advance ensure that the Mental Health Strategy is adequately resourced and advanced in Northern Ireland?
11. What measures is the State taking to ensure that mental capacity and mental health legislation in Northern Ireland complies with the UNCRPD?

## **Article 27**

1. What actions will the State Party take in NI to ensure mandatory pay gap reporting and the introduction of action plans to address the disability pay gap?
2. What actions will the State take to address the Disability Employment Gap in Northern Ireland?
3. What steps are being taken to address challenges in access to employment by disabled people and that action is taken to introduce stronger equality legislation to ensure that citizens in NI have the same protections as their counterparts in the UK and Ireland.

## **Article 28**

1. What actions will the State take to ensure that disabled people have access to emergency relief payments on an equal basis with others?
2. What actions will the State take to address the underlying causes of poverty?

3. What specific measures are being taken by the State to ensure that any requirements to ensure the full protection of the right to life for all people with d/Deaf and disabled people are being addressed?
4. What actions will the state party take to ensure that disabled people have access to justice on equal basis with others in NI?
5. What actions will the State Party take to ensure that there is effective monitoring of the UNCRPD in NI?
6. How will the State develop indicators that will relate to the UNCRPD and be comparable against other devolved nations and internationally (and be inclusive of Deaf and disabled children and adults)?
7. What action will the State in Northern Ireland take to ensure that changes to disability related benefits as a result of welfare reform which negatively impact upon disabled people are mitigated against?

## **Scottish Government**

1. What is the Scottish Government doing to recognise the unrelenting crisis that disabled people have been facing for decades and the interlinking and intersectional barriers and the cumulative impact on disabled people?
2. What is the Scottish Government doing to ensure its commitment to human rights in the social security system translates into practice?
3. What is the Scottish Government doing to improving the decision-making processes for disability benefits that have the effect of reducing delays and reducing the number of enquiries, complaints, redeterminations and appeals?

- 4.** How will the Scottish Government ensure that the forthcoming independent review of Adult Disability Payment is coproduced with disabled people, sufficiently resourced and has appropriate terms of reference to enable a thorough and effective investigation, and planning for improvements that progress disabled people's human rights to social protections?
- 5.** When will the Scottish Government end social care charging?
- 6.** How is the Scottish Government addressing the crisis in social care and the detrimental impact of this on disabled people's right to independent living including their physical, mental and financial wellbeing and their rights to choice and control and their right to play a full and equal part in their communities?
- 7.** What steps is the Scottish Government taking to progress the National Care Service Bill without delay, putting disabled people at the centre of discussions and retaining the original vision and aims?
- 8.** Will the Scottish Government acknowledge that some disabled people are still at high risk of Covid-19 and put in place protections including providing information about risk levels, mask wearing in health and social care settings and ensuring access to booster vaccinations and other treatments and support to help alleviate against loss of income, and isolation?
- 9.** Will the Scottish Government set and deliver clear targets for moving people out of hospitals and institutions into independent living accommodations, and ensure transparency in the use of funds for housing people in the community?
- 10.** What is the Scottish Government doing to reduce poverty amongst disabled people?

- 11.** What is the Scottish Government doing to ensure disabled people who use health equipment at home, including life-saving and equipment for independent living, are able to do so without incurring significant energy costs?
- 12.** What is the Scottish Government doing to provide accessible employability support that is specifically targeted at disabled job seekers?
- 13.** What is the Scottish Government doing to ensure all government bodies and service providers are trained in meaningful disability competence?
- 14.** What is the Scottish Government doing to support the continuation of existing and development of new DPOs?
- 15.** When will the Scottish Government reopen the Independent Living Fund Scotland to new applicants?
- 16.** What is the Scottish Government doing to ensure consistency in the provision of accessible government information?
- 17.** What is the Scottish Government doing to maximise the income of disabled people?
- 18.** Will the Scottish Government require advice and support services, funded by central or local government to instigate full disability inclusion and competence in their services?
- 19.** Will the Scottish Government Commit to changing the law so that Deaf BSL users are able to serve on juries?
- 20.** Will the Scottish Government work with criminal justice partners to ensure the Easy Read Letter of Rights is widely accessible and made available to individuals as a matter of course?

- 21.** Will the Scottish Government produce and implement lived experience guidance which sets out the principles and steps for meaningful participation and which recognises the value of the collective and individual voice?
- 22.** Can the Scottish Government clarify how it ensures that due consideration is given to disabled people's views in consultation processes, including the weight it gives to responses from DPOs which represent the collective voice of disabled people?
- 23.** What is the Scottish Government doing to monitor and respond to public attitudes towards minority protected characteristic groups and what steps is it taking to challenge prejudicial discourses that emerge?
- 24.** How is the Scottish Government raising awareness of, and encourage respect for human rights amongst the general public?
- 25.** How does the Scottish Government ensure school children are educated about the impact of discrimination on minority groups?
- 26.** What is the Scottish Government doing to improve the collection and publication of intersectional data, including by impairment type?
- 27.** Will the Scottish Government amend the relevant regulations to require public services, when carrying out Equality Impact Assessments, to consider the impact of policies and services on people with more than one characteristic so that they can identify and deliver appropriate action?
- 28.** How will the Scottish Government ensure its forthcoming Disability Equality Strategy establishes and delivers on robust and transparent measurement processes, and that progress is monitored at quarterly intervals with recourse to DPOs and the lived experience of disabled people?

- 29.** Will the Scottish Government set up a mechanism and a system of human rights-based indicators to permanently monitor the impact of policies and programmes on disabled people?
- 30.** How does the Scottish Government collate and track progress on meeting recommendations made via various mainstream Scottish Government groups, and action plans?
- 31.** How will the Scottish Government ensure its forthcoming mainstreaming strategy is adequately resourced, and that its delivery and impact is monitored, evaluated and progressively improved?
- 32.** What steps is the Scottish Government taking to work with DPOs to address the Committee's recommendations?

# Annex C:

## Voices and lived experience

### Article 19

#### **Social care cuts and failings**

“The group felt the Government had failed to protect their rights under Article 19 which is the right to Independent Living as many people are living in hospitals and care homes because there is a lack of money and will to support people properly in the community.”

“Friend has had repeated attempts to massively cut her care budget – has happened I believe three times over the past seven years. I want to get on the record this is absolutely due to austerity. The Local Council just doesn’t have the budget anymore so they are repeatedly going back to the same people, going through the horror they are not going to get the support they need to stay in their own homes, so three times within a small number of years having to face the horror that they are trying to get her out and force her into a home. She has a care budget and was choosing to use carers that are most expensive than the recommended hourly amount from the Council, she found cheaper agencies were not providing a good enough service so she chose to go to a more expensive carers on fewer hours and the local authority used that as an excuse to cut her budget to that smaller number of hours but on the same rate as the cheaper local authority and has to find the difference from her own pocket. She is on a zero hours contract as a lecturer so really doesn’t have this money. She can’t spend as much money on food ..etc as a result.”

“People with disabilities having to move out of area for support.”

“Fears that if we contacted eg social services [for support] we might be deemed incapable of looking after ourselves and persuaded into living in care homes.”

“My daughter had a brain injury. That she had no support or rebilation. Infact as I tried to get her support we had intimidation used against us . I also work in 3rd sector and support families with children with disabilities. That are constantly Gaslighted. Lied to or intimated by front line professionals when families speak up trying to get support”

“I contacted social services for a review and it took them four months to get back to me.”

“I lost my Social Services Care budget in 2017 – for my severely disabled bedbound son. I had 4 care staff. It wasn't enough but it was at least that. £45,000 a year. Social Services took it all away without any review and has just left me to care on my own for my son 24/7 without any support. I work 19+ hour days and am often woken in the night so never get a good night's sleep. I do the work of 4 people. I also have to do Occupational Therapy, physiotherapy, social services job too. As an "Unpaid carer" I am treated like I am the scum of the earth... For the first year after the care staff were taken away, he was evicted from his home and spent a year living in a shed in my garden.”

“Disabled women with high support needs, and less frequently disabled men, may be left with little ‘choice’ but institutional care homes after domestic abuse because of a lack of suitable housing and an assumption

they cannot cope in the community (or their care costs too much). Assessment of care needs does not include an assessment of the risk of domestic or other abuse.”

“In summary, the under-resourced CQC regularly gives ‘Good’ ratings to homes riddled with abuse, rooted in its focus on compliance with standards rather than ethics, safety, or independent living.”

“Health and Social care system which is a ‘Demand avoidant system – many disabled people are at the end of the queue’”

“Things are moving backwards for disabled people everywhere and especially independent living. There are more cut-backs on the way. I believe that funding-wise disabled people are bottom of the pile.”

“No responsibility is ever taken – central government blames local government who blames central government.”

“Many disabled people are turned away, hours reduced. £8bn has been removed by the government from social care”

“The experiences attendees shared of using Social Care were not good. The Local Authority outsource the service to care agencies and it was felt that they did not give the adequate care to disabled people. The care providers, it was felt, did not take the disabled persons needs or requests into consideration when appointing carers. No fixed time was given for carers to attend which left disabled people in need and unable to plan their day accordingly. When contacted by disabled people, the Local

Authority appeared ‘not to care’ by saying there was nothing they could do to help.”

“Despite requesting a woman carer to help me wash, I would sometimes be sent a man. Some carers would not help me shower and I could hear them rummaging around in my personal belongings which was very upsetting. I do not feel I could apply for care again in the future if I needed it”.

“Recent research emphasises that cuts to social care lower the health and wellbeing outcomes of disabled people and highlights the impact political decisions have on disabled peoples’ lives, and the risk to life that results from health and social care policy that opts for short-term electoral and budgetary advantage over the interest of the whole community”

“assessment process [for Augmentative and Alternative Communication] that is that is considered highly discriminatory by many disabled people and their families”

“Also Continuing Health Care funding for support with living in the community (article 19) Funding is being cut even more. Some people are losing 50% of their Personal Health Budgets. It is a continuous fight every year to get or keep the support people need and you have to fight over and over again. It is exhausting and many people just give up. All help people need is being restricted and the rules get changed all the time. There are also too many people to deal with rather than just one person who knows you and your conditions,”

“I have MS, rheumatoid arthritis, heart problems, COPD, I only have one kidney, I have tumorous cancer, Hepatitis from a blood transfusion, cellulitis, a melanoma and edema. I need social care support, having fallen over a number of times, but Newham Council won't provide it because I own my own home where I lived with my husband. I worked all my life – around 38 ½ years – paying tax at the 40% tax-rate, I made thousands of pounds of savings but it all went on adaptations to the house when my husband fell ill... I also took out loans to make more adaptations and those had interest on them and so now I am thousands of pounds in debt. Newham Council say I have to pay for my own social care support but I can't afford it. They say if I sign my house over to them so they get it when I die then I can have social care support from them now. I won't do that. But it means I can't have an operation I needed. I have had 8 mini-strokes and a heart attack and I need an operation. But I wouldn't be able to manage when I came out so I can't have it.”

“The Council also takes so long to respond to requests for support. Our GP asked for a social worker and equipment and incontinence pads. That was in the February. We heard nothing. We finally heard back from Newham social services in March – a few weeks after my husband had died.”

“Simon has always had the impression that obtaining a diagnosis for his dual diagnosis of Autism and ADHD, would be a gateway to obtaining the support he needed to enable him to manage his life and have the opportunities that other people have. Unfortunately, Simon has experienced that this is not the case and he has spent many years, since diagnosis, trying to manage, trying to co-ordinate his own care, trying to communicate his needs and fighting for the system of Health and Social Care to meet his assessed needs.”

“XXXXXX Council cut disabled people’s services by 1.3 million in the 2021-22 budget . These cuts included a £31,000 cut to the council’s Equalities and Diversity budget, and the closure of three respite care homes. The ruling XXXXXX Party group members seek to obfuscate the reality and scale of the cuts, by referring to them as “efficiency measures”, “streamlining of service”, “rationalisation”, “savings,” and similar politically preferred language. In April 2021 local members of the XXXXXX Party were instructed by senior party role holders not to refer to the cuts as “cuts.” XXXXXX Party councillors—including disabled councillors—are ‘whipped’ to vote through the cuts. Voting against the cuts would result in disciplinary action, including the threat of having the ‘whip withdrawn’ i.e., suspension from the XXXXXX Group / Party. In April 2021 two XXXXXX Party councillors told two town councillors they would be “reported” for raising the cuts to disabled people’s services at a town council meeting, and that they should remain quiet as speaking out would “worry disabled people.” One of the [local] councillors told members they were “proud” of the budget. This behaviour is illustrative of a local political culture which is institutionally hostile to disability rights activism, with widespread ignorance of disabled people’s rights, and of the social model.”

“I know someone whose son died who had Down’s Syndrome. He had to take laxatives on a regular basis and avoid certain foods due to his intestinal problem and that poor man died with 25lbs of faeces in his intestinal tract because it ended up rupturing and that was because there was no one making sure he took his medication on time. They didn’t want him to live in a care home setting so he was in supported housing and he enjoyed the freedom but should also have been getting the support.”

RB is a young adult who attended a specialist school until the age of 16. They had a series of subsequent placements in supported living accommodation, all of which broke down due to ongoing behavioural and

addiction issues which were not adequately addressed by their funded level of care. We raised safeguarding concerns with the local authority. Their response was that RB had capacity to make unwise decisions. RB eventually became homeless, despite desperate attempts by their mother to secure further support to safeguard them. Living on the streets, RB became target for local drug gangs. We supported RB to secure urgent council accommodation pending further needs assessments under the Care Act 2014. We raised multiple safeguarding concerns with the local authority about the urgent nature of risk to RB. The local authority did not put in place adequate interim support pending assessment, and RB again fell victim to local drug gangs and “mate crime”. RB became suicidal, making attempts on their life. RB was eventually admitted to hospital.”

L is a young adult with Downs Syndrome and learning disability who used to attend a day opportunity for 3 full days per week. He lives in residential care. L has recently been told that the day opportunity cannot meet his continence needs without 1:1 support to assist him. Requests from L’s family to the local authority for appropriate support to continue to meet L’s needs during the day have not been responded to. L’s four friends, whom he lives with, continue to travel to the day opportunity but L has to stay at his care home. He does not have additional 1:1 support to leave the care home to explore any other community-based activity. He is unable to leave his care home Monday to Friday. We are currently advising L on a range of rights, including his right to liberty.

T, a 36-year-old man, lived in a London Borough receiving care and support in his supported living accommodation. Towards the end of 2019, his needs for care and support increased when his mother died. The funding panel turned down his social worker’s application for additional hours to meet his increased need. The situation spiralled and T was admitted to hospital following self-harming. He lost his accommodation.

On discharge from his local hospital ward, he was allocated council accommodation and offered a limited and inadequate number of 'outreach' hours to help him go shopping every week. His council accommodation was a basement flat within a larger block, and only had one very small window in the bathroom which did not open properly. T was not supported adequately, and regularly urinated over his home, was not able to clean effectively and lived in squalor by the time he was referred to us. He urgently required an uplift in care and support, which had it been implemented in 2019, would have avoided significant inhuman and degrading treatment."

In the early weeks of the pandemic one disabled person told Inclusion Scotland: "I've got reduced lung function, no immune system and chronic brittle acute asthma, I've become bedbound and have a bedside commode which doubles as shower chair. My care has been cut from 2 personal care calls a day to ZERO."

"I completely understood Covid-19 was an emergency – no-one saw it coming. But what you can cope with for a few weeks then turns into months and this is not sustainable – I didn't have a shower in 7 months."

"This is possibly one of the major problems in Scotland today for disabled people. They hear about this mythical beast called "independent living" but their own circumstances show how much that does not apply to them. There needs to be a lot of change to enable disabled people in Scotland to enjoy their right to Article 19 of the UNCRPD. This Article impacts on so many others within the UNCRPD such as adequate standard of living,

health, housing, transport, information etc. that all need to work together if independent living is to become a reality for disable people in Scotland.”

One client says that she feels she is treated ‘worse than a dog – at least dogs get taken for a walk every day’ – as she spends all but a couple of hours a week in bed. She doesn't have a [support] package flexible enough to have someone around to help her back to bed when her muscles no longer allow her to maintain her position in her wheelchair. The hour that she can spend in her chair, while the care worker is doing housework, she drives from room to room like a caged animal ‘just to make sure the other rooms are still there!’” Personal Budget Support Worker<sup>484</sup>

R received support from the ILF. After it closed his Local Authority nearly halved his daytime support hours and removed support at night altogether. There was no explanation why. R has a degenerative condition and his needs have increased. There are various unpredictable risks that support at night was needed for, including problems with his ventilator and assistance to change position to avoid pressure sores as well as support to access the toilet. His Council argued that using incontinence pads would increase his independence at home. The idea of being forced to be incontinent has all sorts of implications in terms of health (eg it increases the risk of urinary tract infections), relationships and ability to continue in his job.<sup>485</sup>

Michele Vaughan, who has now left care work, told the Bureau for Investigative Journalism that during the pandemic she discovered an

elderly client had a catheter whose urine leg bag had not been changed in more than a week.<sup>486</sup>

“Older people were left high and dry. So many had home care terminated or reduced. And they relied on those visits to help them get fluids. A lot just stopped drinking because they feared they could not get to the toilet.” Nurse Lesley Carter from Age UK<sup>487</sup>

Angela’s afternoon carer had been off sick the day before, which meant that Angela had not had anything to drink since 2pm the previous afternoon. She finds getting a drink for herself very challenging: the involuntary movements of her head and arms makes co-ordination and turning on the water taps difficult. Her afternoon carer usually leaves her something to drink, but didn’t on this occasion, because she didn’t come to work. So Angela woke up at about 4am, thirsty. By about 5am, Angela was so thirsty that she decided to get out of bed, climb into her motorised wheelchair and travel down the road to the 24-hour Asda to buy a drink. She said that staff at Asda helped her.<sup>488</sup>

Amanda Richards died in a fire at her Coventry home after funding that had provided her with 24-hour care was cut. She was a wheelchair user and had a degenerative neurological disease that affected her coordination. A review into her death found that there was an inadequate risk assessment carried out into the dangers of leaving her unsupervised for two hours each day. A serious incident review by the Coventry safeguarding adults board stated this week that insufficient attention was given as to whether the existing package of care needed to continue, and

that the report also found that relatives' concerns about the sustainability of the care plan had not been properly considered.<sup>489</sup>

“Viewed through the lens of complaints from the public, and our impartial findings, the adult social care system is progressively failing to deliver for those who need it most. Increasingly it is a system where exceptional and sometimes unorthodox measures are being deployed simply to balance the books – a reality we see frequently pleaded in their defence by the councils and care providers we investigate.” Local Government and Social Care Ombudsman

“Around 60% of my day to day work involves dealing with complaints relating to care agencies. This involves carers not arriving on time, missed care visits, incorrect administration of medication and poor quality of care.” Anonymous adult social care social worker

Disabled people are being forced to remain in hospital against their will due to not having a care package in place. They are then told by healthcare workers that they are bed blocking and threatened with being discharged into a nursing home. This is bullying. It prevents people with disability from living independently in NI. Furthermore, many OTs in the community do not have the knowledge, funds etc to ensure that their clients receive the correct appliances at home to enable them to live independently. There are only very limited amounts of equipment available for the person to be rehabilitated/reenabled at home. This can be blocked further by Occupational Therapists, Doctors etc., pre-discharge/

I have had to fight really hard to get even a little bit of support that I need to be able to live independently, I think that this might be due to not "obviously" looking disabled as my support needs are a combination of mental and physical health issues. The only reason why I knew how to fight for some of my needs was due to the employment sector that I am currently working in. Others are not in that position.

## Social care charging

"Social care provision was brought into the conversation noticing that local authorities are charging more, leaving disabled people on benefits to pay more for their support."

"Look at social care. It's going backwards. Most LAs have introduced charges and these fundamentally disadvantage Disabled people."

"I hate that social care is so separate from the NHS and I hate that the principle you are treated when you need to be is not upheld in social care. As a former GP I have seen this."

"No guidance on financial assessment; all decisions seem discretionary; depends on council and county."

"Some of my friends are having to choose between eating, heating their homes and paying for care because of the charging policy."

"a requirement for their financial contribution... can leave people with disabilities financially challenged and with ongoing, assessed, but unaddressed needs."

“During the financial assessment, he was informed then that judging and looking at his income that he would not need to make any contribution to his care package. However, he was very surprised to see that he had in fact had to pay for his care. Something which to this day he believes that he should not have to pay, especially seeing as that the stroke, the falls that has led to a cracked L1 vertebrae which has caused him is all at fault with the council, especially with housing. If they had only listened to him and me in the first place... None of this would have happened. And now he’s being summoned to court for the outstanding payment which is causing him further anxiety on top of his current circumstances and I fear that he may suffer from another stroke or heart attack which is bad as I do not live at the property, or he may self harm which he has done in the past. He has now been summonsed to court for non-payment. I am truly at my wits end with this and its now causing me sleepless nights.”

“It used to be that social care enabled me to live a fuller life and I got support to go out and about and see people. Then came the cuts – and that was before COVID. Things had already been stripped back but I’m worried sick what support will be left at the end of this.”

“Paying for support makes things worse.”

In adult social care we are seeing more and more elderly and disabled people cancelling their care, despite being assessed as eligible for support under the Care Act (2014), due to financial reasons. The only income for the vast majority of the individuals I work with comes from a state Pension/benefits. Although they are advised that they will be left with money to afford their day to day expenses, understandably, this provides very little reassurance, as it is difficult to afford the basics in the first

place. The stress of paying for support is overwhelming for many people—paying for support they need to meet their most basic needs and to live a life of dignity, such as accessing 3 meals a day, and support with personal care tasks.” Anonymous social worker

“I was told by one member of my funding panel that my ‘problem’ is that I think I am here for the people whereas she understands that her job is to protect the local authority.” Anonymous social worker

“As a parent carer I already have to fight for every limited support we get for my child and social services for adults with disabilities is considerably less well funded than for children so I see no evidence that my son will have access to support required for independence in adulthood. Existence of places like Muckamore and huge lack of specialist accommodation in local towns means my son will have no option but to remain with us until we are no longer fit to care for him. Terrifying prospect and huge emotional burden on his sibling.”

## **Institutionalisation and abuse**

“People also felt that people with learning disabilities were more at risk now from being abused, tortured and treated with less dignity and respect. people talked about the abuse scandal at Whorlton Hall and how many other hospitals and care setting have been rated inadequate and staff found guilty of abuse but yet care companies have been allowed to keep contracts, Cygnet who owned Whorlton Hall being one of them who have still got contracts... some [event participants] do not feel free and safe in care homes and hospitals”

“Over the past 5 years, there have been reports after report all affirming that psychiatric hospitals subject inpatients to brutal and inhumane

treatment that the Government refuses to address by mandating a programme involves moving everyone out of such institutions into the community with the ultimate goal of ending institutionalisation of disabled people”

“People with learning disabilities are still being locked away in institutions (Assessment and Treatment Units) and continuing to be treated badly and isolated from families (Winterbourne View and many others).”

“All the independent reports affirm that people with learning difficulties and autistic people detained in hospital are routinely subjected to chemical and physical restraint leading to inhuman and degrading treatment.”

“The conditions in these mental health institutions have not changed since Panorama’s exposure of Winterbourne View Hospital scandal first broadcasted during 2011. People with learning difficulties and Autistic People are still routinely being abused, treated inhumanity and dying in state-sanctioned institutions.”

“2000 autistic and learning-disabled people are locked up in inappropriate institutional settings. Government has failed to move them into community-based support.”

“This country has a long history of institutionalising people just because they’re seen as different.”

“the government continues to authorise both the use of restraint on grounds related to mental distress”

In 2019, the Mental Welfare Commission for Scotland found “evidence of restraint being an issue in 20 of the 54 individuals we visited (16/28 in hospital, and 4/26 in the community)” and noted that this is also distressing for other patients in the vicinity – “Patient has not required restraint although during discussion it was apparent that he sees others becoming distressed and restrained. This induced anxiety for him.”

“We spoke about Margaret Fleming who was not given support to make her own decisions. She was killed by the people who were supposed to be caring for her. We felt angry and upset about this. Every person with a Learning Disability should have the right to make their own decisions. Instead, we can have our right to make decisions taken away through Guardianship law. People First is campaigning to change this.”

“One time I was called and he was being kept in the cloakroom with the door shut on his own incredibly distressed and not allowed out until I arrived. He was 5 years old with the mental age of a three year old... X very traumatised re the holds and not sleeping well and screaming in his sleep, very reluctant to go into school...”

## **Forced detention and compulsory treatment**

“Particularly difficult for black males currently. The UN guidelines don’t get down to ground level. You can quote the UN in a tribunal and say that coercion is against their belief system but in reality having your rights upheld is difficult because the law in the UK doesn’t support human rights.”

“Private mental health hospitals are keeping people there because it’s a cash flow issue.”

“In the case of people judged to ‘have capacity’ who are not consenting to ECT, ECT could still be allowed if the Responsible Clinician regards it as necessary to save a person’s life, or to prevent serious deterioration, and if court approval has been obtained. In the case of people judged not to ‘have capacity’, ECT will still be allowed if both the Responsible Clinician and a Second Opinion Appointed Doctor (SOAD) agree that it is required.”

“Detaining people is not care. One time, my son was sectioned and, because he cannot stand sounds (he has autism and so gets agitated) he said to me: ‘If you don’t get me out, I will stay here for life’. It’s just so sad. Two of my clients have been abused in hospital – when they were sectioned there. It’s left to them to prove it. How can they when they’ve been traumatised?”

“The worst thing I felt was you had no power and they could do what they liked to you.”

“demise amongst brutal issues from psychiatry”

“I was only in for eight days and I was totally traumatised.”

“There need to be a move toward autonomy – coercive and forced medication left me depressed and suicidal.”

“our rights to believe what we want, and to religious freedom. But if you say you hear the voice of God or experience something unusual the first port of call is to drug you. This approach is not trauma informed and doesn’t take a person’s life experience into account.”

“A participant had experienced coercion of medicine – this was traumatic”

“My daughter suffered from psychiatric abuse.”

“One participant described himself as a black gay man under CTO, who has been brutalised and traumatised by the mental health system”

“Sectioning experience is traumatic – ‘I’m quite well spoken/eloquent but many people aren’t who are suffering at the hands of the Government and NHS.’”

“there is a problem with the whole idea of someone doing something to you ‘in your best interests’ and giving you no choice. I’m against forced mental health treatment in all forms, whether it’s CTOs or sectioning. Institutionalising people in care homes or hospitals causes irreparable damage. The whole psychiatric system is coercive and controlling. I would prefer non-hierarchical support because I do find mutual aid helpful.”

"In 2017 due to lack of staff my son's independent living package collapsed. He now lives in a care home 80 miles from his home town."

## Inaccessible and unsuitable housing

“I know someone in [xxxx] and they are the carer for their brother and they have been in a flat that is not only inaccessible but also bad for them and there is no way to get anyone to listen that they have rights.”

“I became disabled through illness in March 2019, effectively becoming housebound in a rented flatshare in Camden as I could no longer climb the stairs. I was admitted to hospital in May 2019, and filled in a homeless application via Camden council in July 2019. In September 2019 I was essentially forced to accept unsuitable temporary housing upon being discharged from hospital, where I was trapped due to inaccessibility for two years, where I was not able to access the bathroom.”

“When he came out of hospital he was put in a nursing home for older people and people in palliative care. It was very bad for mental health”

“People also felt that they have less choice about where they live due to shortages in housing”

“[my son] has been "prescribed" adaptations to this house to make it safe for him to use his wheelchair and enable him to get out, but the landlord, council and support agencies have made this impossible and refused to follow the law. The injuries my son received from his fall were never treated and although the broken bones have healed he can no longer use his hand properly or walk safely. When I began complaining about this my Landlord "punished us" by first trying to evict us and make us both 'street' homeless and then by cutting off my heating and hot water completely.”

“there are still problems with accessible housing – still battling with the Local Authority who are unhelpful about damp”

“Lack of social housing. Disabled young people having to live in care homes for the elderly because no accessible accommodation.”

“[local authority] thousands wasted on adaptations to improve life, still years on forced live in cell 11x11ft, the misuse grant monies was beyond belief,... Basic the company used to make wet room safe follow fall, failed,... but then the massive issue's began, electric wire's left bare...rat infestation... sleep in lounge”

“This argument between [the Council] and me went on for nearly 3 years... I then decided to use my student finance allowance to help... All this time the water was still gushing and coming through the floors boards in the kitchen making it perilous to enter for an abled bodied person let alone someone who is unsteady on his feet and prone to falling down...because of the stress that he was under and the constant high [Blood Pressure] that he was having for several years (even prior to the water gushing under the floor boards in the kitchen) that he had a stroke.”

“The tragedy at Grenfell Tower, showed that evacuation processes are not always correct. Risk assessments were wrong. Even in stay put buildings which are presumed to be safer, if the fire enters your flat you have to escape. PEEPs would assist in safe evacuation. How can a landlord put a value on my tenancy, but no value on my life?”

“I now need to use a wheelchair but I live on the second floor. I have applied to my housing association (and others) for a move to somewhere

on the ground floor, it doesn't even need to be wheelchair accessible, I just need to be able to get a wheelchair in and out. Basically there is no provision, I just have to wait for someone to move out, and I'm not in the highest category for needs, so it's probably going to take years, and I might never get a move as there will always be someone with a greater need than me, I've been waiting 10 months so far.”

“I’m considered homeless as there are no homes which meet my accessibility needs in local area”

“There is not enough supported housing for people. The points system is challenging as often you cannot access enough for social housing – the point system needs reviewed to recognise the needs of disabled people who can face challenges in accessing private housing. It must get to crisis point before something is done and that can be too late. It is not fair to ask families to step in and support, particularly if they are older”.

“We have significant housing issues as a couple and one of us uses a wheelchair sometimes when having issues with artificial limbs. We got a new front door, and no one even thought of making sure it was wide enough for a wheelchair. So, when it’s fitted only to find out it’s not wide enough for a self-propelling wheelchair, when you bring it to the attention of the Northern Ireland Housing Executive you get back oh it’s a big job and they put you off getting it sorted and you are told to use back door instead. I feel someone within the organisation should be fighting for the disabled person and we should not have to speak about it and that person should get it sorted. It puts a barrier up for us to not bother asking for things and just put up with it.”

## Article 27

### **Discrimination in the workplace**

“Furlough made it easier to get rid of disabled staff who were struggling due to lack of reasonable adjustments.”

“Worked for the NHS for 12 years – became unwell and had a supportive team. However, a new manager questioned her ability to travel for the role – X resigned and has been unable to work after COVID. Advised by trade union to challenge the disability discrimination. Feels that people are allowed to get away with disability discrimination.”

“I think it is more different for people with hidden impairments... But people at work don't see all these. I am expected to do a lot of over-time. I get bullied at work and go home really upset. It brings my blood pressure up and had to have stress leave. There is no sympathy for me as a disabled person. I get laughed at more. And this you have to understand is in the NHS. I work for the NHS. I get mocked for always having something wrong with me and being off sick and management don't understand. I have a colleague with Crohns disease and she was told she was not allowed to use the toilet except on official breaks.”

“From my own experience as a registered mental health nurse with disabilities, discrimination in the NHS is much worse than I expected and so is bullying for speaking out.”

“I have two degrees a Bachelor and honours degree and a Masters. Yet no-one will employ me due to my disability. They get away with it because

the feedback or reasons given are enough to satisfy a glancing review. The only reason my brother is working is because the company he is with are all sufferers of mental health challenges as well and use their lived experience to help others as it is a social enterprise. Without them he would never work anywhere due to his health. I cannot work in conventional jobs due to my disabilities and access needs. Places would rather turn me away then spend money so I can do a job. I'm now having to try get another degree, fingers crossed, in teaching as I believe it's the only route left open to me. Otherwise, I will be on benefits for the rest of my life or until I am forced to take that life. This is the harsh but the brutal reality of the situation."

"I have to continue to prove that I am disabled as my managers will not make adjustments that would make my working life any easier. My employer seems to restrict the opportunities for disabled people or persons with health issues. The majority of promotion opportunities require you to agree to work full time and are not open to people who are unable to work full time. My employer is struggling to meet the requirements to have a certain quota of disabled people in higher positions but is unwilling to make the changes required to actually accommodate such candidates to apply and succeed."

"Disabled people seem to be considered a drain on society. Employers only seem to want to recruit people who can work full time and seem to view anyone with a health issue/disability as a drain on resources, that they will need extra support, which to the employer equals cost, and that the person would be unreliable and be off work sick more often."

"I have been personally disadvantaged by the lack of parity of legal protection compared to other areas of the UK. In 2009 my employer

required me to attend an occupational health assessment of my mental health. This direction came out of the blue, I was not ill, and I subsequently discovered that I was not told the real reason for it. This began an ordeal involving an increasingly toxic working environment which ultimately led to my transfer to a different Department in 2016. The reason given for the transfer was that over this period I had raised 4 separate but related grievances, none of which were upheld by my employer. I received a written warning for major misconduct. In all 4 grievances, I asserted my right to be protected from disability discrimination. The Equality Commission NI subsequently supported my complaint of victimisation on grounds of disability. In response my employer attempted to have the case struck out on the basis that I was not in fact disabled and therefore did not qualify for protection under DDA. They subjected me to the indignity of insisting sight of my full private medical records before conceding this point to the Tribunal.

The initial legal opinion was that I had a strong case, however a later review resolved that this was based on an assessment of English case law where claimants had benefited from protections under the Equality Act 2010 and crucially, the removal of a loophole relating to victimisation. The opinion was that the strength of my case was significantly weakened by this discovery, lack of parity in NI law. The Equality Commission withdrew support for my case, and I eventually negotiated a settlement with the assistance of the Labour Relations Agency. The experience effectively ruined my career, it also led to a mental breakdown involving intense suicidal feelings that I was extremely lucky to survive. I think it is an absolute disgrace that the NI Assembly have done nothing to remove that loophole or address the many other ways that people with disabilities living in NI are disadvantaged by gaps in our book of law.”

## Employment barriers

“I tried really hard, worked so hard for it and I felt the job centre really weren’t that interested in me, .... You have to show evidence you are making an effort to find a job and I felt really let down by the system. Sometimes Deaf people are shoved aside. I’ve had enough of it really. The job centre in particular I think... It’s about setting up systems so Deaf people can have interpreters when we need them. Without them we become stuck, we are held back in life... I think for Deaf people there is so much discrimination it is hard to come back after those knocks, especially when you are looking for employment, it is a hard thing. I feel like I am down here and all the jobs are up here. I have a brother and he has a job, he has had a good education, he has had a lot more chances than me because he is hearing and he hasn’t had the same barriers to education and access to information and he manages to get jobs...a real inequality between myself and my sibling.”

“My experience with a lot of Deaf people has been that they give up their jobs because of the communication barriers/language barriers at work. We encourage Deaf people to have their dreams but it doesn’t become a reality for them because of the barriers that they face.”

“In the 1990s there was work going on where Deaf people were advising jobcentres on how to be more inclusive. It’s like it’s gone backwards. Why do we have to keep fighting? It’s really worn us out.”

“It is ironic that the system and process implemented to support and accommodate disabled people [Access to Work] into work is unsupportive”

“In large public organisations, staff with disabilities are bullied and do not get the accommodations they need to do their job successfully.”

“A staff member she managed found the Access to work process mortifying and difficult, with significant barriers including time delays, bureaucracy, unclear expectations on the sourcing and delivery of equipment”

“You have to fight for [Access to Work] – lots of people have quit; many people don’t have the support mechanisms or resources – very damaging to health”

“Employers are more frugal now – everything is about money even for needs that were not a problem before to meet.”

“Continued exclusion from employment, access to work scheme cut, progress in understanding needs of disabled folk has reversed. My workplace NEVER considers my needs when planning away days, training, social events. I am utterly excluded. The equalities officer did negotiate reasonable adjustments for mandatory training. It's the enormity of it, everything is a battle.”

“Employment tribunals – 3 months and one day is far too short a time and is a timeframe that can be impossible for people to meet in a number of circumstances, for example if they are hospitalised or having a breakdown – putting all their energy into surviving with none to spare at that time to take a case.”

“I think things are definitely getting worse. When I had a work station assessment at work this time round, I had a massive battle to get the

equipment I need. They argued that because I only work at this job one day a week I can hot desk. I challenged the outcome of the assessment and was ignored. So I referred myself to Occupational Health and they bought me a chair and a footstool and the equipment I needed.”

“employment situation has improved I believe”

Not enough part time work for disabled people. Not enough acceptance of working from home without good reason. Not enough appreciation of autistic needs and skills in order to get and hold down a job. I have two degrees and many excellent skills, but am unable to work.”

“I worked part time. I day a week I had to go into the office. My employer made adjustments so that I could work from home. But it was necessary to go in one day a week. My care providers do not consider having to go to work and feed 45 enough reason for them to guarantee an early call in the mornings. I was told we don't have clients who work so to them it is not a priority. The reason they don't have clients who go to work is because they don't assist you to get ready for work. Not because disabled people don't want to work”.

## **Article 28**

### **Distress and trauma caused by benefit assessments**

“We supported a refugee woman who survived genocide and being shot, who needed to be spared the WCA interview where you have to go over what happened to you. The assessor company, the Centre for Health and Disability Assessments (CHDA) — Maximus — dismissed as insufficient, a letter from the clinical physiotherapist referring her to the Pain Clinic and verifying shrapnel in her body from surviving a bomb blast. An in-depth report on her trauma from the PTSD lead doctor at the local hospital was similarly discounted. The doctor complained to Maximus that she is called

as an expert witness in court cases and her professional opinion had never been dismissed before. After intensive advocacy, we were able to secure exemption from interview.”

“The assessor companies pressure women and girls to undergo interviews when this is too stressful and many want a paper-based assessment. Medical evidence by doctors much more qualified than the assessor (who can be a physio or ambulance man) is often dismissed. Often, assessors only make a token effort to reach doctors and practitioners for their opinion to accompany the paper assessment. Hence they often don’t reach them and make decisions based on ignorance and bias.”

“I had to pay a NHS practitioner privately for a report to support my benefits claim – I was no longer part of her clinic, but needed her written report. The DWP blames applicants for not providing correct information in claims, but the NHS won't provide it. It means that we have to pay privately (if we can), and keep appealing our claims. It is humiliating, stressful, and leads to mental health problems (eg self-harm).”

“processes for assessing someone’s welfare benefit entitlements are intensive, require significant investment of time, and can be very distressing; for Simon, this is often the cause of extreme distress in advance of an assessment, when assessment paperwork arrives, when seeking clinical and professional evidence, when being reassessed and whilst waiting to receive the outcome. This happens once every 18months and attributed distress can last around 6months. Although there are times when Simon experiences less distress, his ASC and ADHD are permanent conditions for which he cannot receive appropriate care. The disability benefits review processes convey a systemic lack of understanding of the

nature of ASC, the life changing impact it has on someone's ability to work."

"Assessors had not read the forms already submitted so did not know the full extent of their medical conditions and asked invasive and inappropriate questions that left them feeling embarrassed and depressed about their personal situations."

"application process for ESA and PIP completely degrading and creating further vulnerabilities and mental health issues"

"Attendees felt it is too difficult to get any help and support and that they had to 'jump through many hoops' and it shouldn't be that difficult. They felt it was deliberately designed to put disabled people off applying for benefits / social care or other support because it is so difficult, many disabled people give up as they cannot 'fight' anymore or suffer with their mental health because of the assessment."

"I have done this more than once but nothing changes so I will no longer waste my time raking up how awful anything to do with [Department for Work and Pensions] is, it is too distressing"

"There are so many bureaucracies that you must go through to get any help. Do they think you are in a wheelchair for a laugh. I was asked if I could walk 50 metres, I am visually impaired so how do I know how far that is".

“National Federation of Blind access to support or mobility and skills training: squeezed out of social care. Far fewer people working here and negative impact on lives.”

“any form of rehabilitation under severe pressure”

“Appalling that disabled people have to pay for letters to confirm our medical conditions.”

“I am not sure if my experiences can help at all but I feel compelled to so that things can hopefully change... The 'nurse' they had doing the interview (ATOS) tried leading questions nearly all the time but the worst part of that interview was being asked to explain all my previous suicide attempts. (I have CPTSD from an abusive childhood mainly but adulthood was also... fraught) she had me explain each and WHY they failed. Going into detail of what I tried, when and why... finally when I had detailed each attempt she hit me with "Do you really think you were that depressed though?" I was confused... I had just detailed several attempts to take my own life... she followed up with "I mean if you had really been depressed and wanted too you would have succeeded!" She pretty much told me that I failed at living and also that I failed at dying. On top of all the things in that interview I had to painfully admit I couldn't do she made me feel like absolute crap for not doing society the favour of ridding myself from it... I have now lost PIP altogether because due to these experiences its actually become a fresh new trauma trigger for me... that undid a lot of progress made in therapy and still has implications even now.”

“Ms A, who has PTSD from abuse, agoraphobia and serious physical health conditions, has suffered repeated stressful reassessments and being wrongly cut off multiple times.”

“people are being put through unnecessary trauma to claim their benefits.”

“the process to the tribunal feels like being criminalized. The process has exacerbated current health conditions and M developed rheumatoid arthritis.”

“I am working with clients who have moved from DLA to PIP and gone from being on FULL DLA to zero PIP. Trying to get DWP to give the right amount of benefit.”

“My son has autism. He cannot cope with the online ESA process; then questions. Received £150 compensation after complaining; process not accessible; assumes everyone can do it; does not give correct information.”

“Ms C is aged 17 and her mother applied for PIP on her behalf after it was suggested by Great Ormond St Hospital. She was asked to travel to a face-to-face assessment by IAS despite her PTSD, physical disabilities and having had COVID three times due to low immunity. IAS eventually agreed to a paper-based assessment in November 2021. However, the DWP decision-maker (DM) seemed to seize on minor improvements against a background of Ms C being severely incapacitated by her immune system illness and after being hospitalised. She was refused PIP, the DM scoring her only a handful of points, saying there was no evidence of need. The

doctors treating Ms C are horrified and said they had not been contacted for their opinion. Ms C's mother has put in for mandatory reconsideration and meanwhile is skipping meals and using her own PIP to pay for her daughter's disability expenses. She says: ". . . the whole year that passed after an application was made has been a nightmare for us".

"J, a severely disabled woman in the East Midlands was cut off benefit for "failure to attend" a home visit. The appointment times allocated by Capita were before she could get herself ready in the morning. She told us that the CAB said nothing could be done and made her feel bad that it was her own fault. She had gone over the age to make a fresh PIP claim, and Attendance Allowance for older people has no mobility component. She lost the first-tier tribunal which upheld the "failure to attend", which she could not go to as it was in another town and she is virtually housebound. With help from the CPAG Upper Tribunal Project, we made a disability case about her ill-health to the Upper Tribunal judge as to why her appeal should be heard late. She was granted £10,500 arrears and ongoing PIP benefit."

"R is a Disabled Asian woman with cancer in XXXXXXX, she found WinVisible online after a bad experience with advice locally. She had been similarly cut off by the DWP after problems with Capita, and due to illness she struggled to submit her appeal papers. These arrived to the tribunal one day after deadline, and the clerk said they would have to consider whether to accept her appeal. We couldn't tolerate uncertainty or her waiting ages for appeal, and we contacted the DWP directly. She got £11,500 in PIP and severe disability premium payments. She said: "While some of the benefits staff were kind, most couldn't care less. I was close to a complete breakdown, and if it weren't for [WinVisible's] help, I don't know how I would have survived." R was cruelly cut off when she needed benefits the most. We don't know whether racism was a factor as well as

sexism and disability discrimination, as officials often assume women are exaggerating illnesses. Being labelled unco-operative and cut off for 'failure to attend' interviews when we are ill, in mental distress or in hospital treatment is a huge problem."

"S had to give up waged work. With an invisible disability, her interview for disability addition to Universal Credit was deemed 'inconclusive' and she was told she had to wait until face-to-face interviews restarted. She was bounced between DWP Universal Credit, the assessors Maximus, and her GP who declined to provide more medical evidence. We used welfare rights guidance to challenge unreasonable delay and she won £4,000 arrears. She said: "Thankfully after what felt like a never-ending nightmare, I have finally got what I had been entitled to. I feel so relieved that I can now afford the diet that I should have been on, I can focus on my health and my children without Jobcentre breathing down my neck about being sanctioned, me having to keep asking for sick notes from my GP and them pushing me to go back to work. I would like to continue with WinVisible support group to help others in any way that I can from my own personal experiences."

"I am a member of a Facebook group for PIP claimants and when I read all these stories from people who are bed bound being asked to go to assessment centres, I realise how lucky I am. Several people in this group have been bed bound for years and the DWP hounds them to go to assessment centres."

"My friend's husband was found fit for work even though he had a heart problem. So he went back to work and about an hour after arriving he collapsed and died. That was about 2018."

"I had my own wheelchair dropped on me by the centre manager whilst accessing a stair lift. It broke my collar bone. This was a direct result of not listening to me or my then carer who both shouted at him in panic not to lift the chair by its mudflaps which promptly detached and the whole wheelchair dropped some 3ft hitting me in the head and the shoulder. None of this could have happened had they not chosen the least wheelchair accessible building to make assessments in."

"Definitely not enough financial support to live on. Access to Social Security benefits has become extremely difficult to the point of impossible due to the hostile culture which demonises claimants and treats them all as if they are liars and cheating the system. The assessment processes are cruel, degrading, discriminatory, depressing, demeaning- an absolute disgrace in this country. Appeals processes are gruelling and designed to make you give up – which lots of people do because they are too ill to continue with the cruel, demeaning and arduous process. Even if you do qualify for benefit, it's nowhere near enough to live on in this country with a very high cost of living- especially if you have additional needs due to disability."

"The impact of these experiences on the health and wellbeing not only of participants, but on their wider family networks has been significant, with most directly attributing acute and chronic anxiety and stress to the process of being assessed and even anticipating the next assessment meeting. On top of this, many participants reported the additional stress and worry involved in complaining about poor, inadequate and incorrect assessments, with some experiencing feeling bullied by Social Services, penalised or 'victimised for complaining'. From the experiences shared in this workshop, the concern is that, as one participant claimed: 'the very system that sets itself up as safeguarding ... is abusing and undermining the rights of people across the country'."

“Having to prove your disability is so hard. It is degrading. It definitely leads to other health issues (especially mental health issues). If someone has a disability for 10+ years, it is extremely unlikely their abilities will change. Yet they have to prove they are entitled to financial benefits throughout their life – it is a disgrace.”

“The assessment does not give a clear and more importantly accurate account of my daily care needs. There are items in it that are astoundingly wrong. This has caused me a level of distress that I am now concerned about as it is affecting my physical and emotional wellbeng.” Social care service user.

“The lengthy processes that you have to go through to prove that you really are suffering from lifelong limiting illnesses is inhumane and degrading.”

## Poverty

“you can’t call a poor person to be part of your group if there is a gap of poverty. You can be friends but you are not equal in the group. Disabled people are given so little money that is a struggle to stay alive.”

“People said that they had not had enough employment choices and that they do not have enough money to live on.”

“The benefits were hard enough to live on previously, but since Brexit, Covid lockdown and inflation rising, there has to be a strict regime of what

we need and what we can't afford. As a couple, my wife and I go without, as we make sure our growing 15 year old daughter gets what she needs.”  
“financial poverty so that choices of eat or heat are everyday reality”  
“Disadvantage, poverty and digital exclusion are all being more firmly entrenched”

“Benefits being slashed and people being forced into poverty”

“most disabled people are forced to live in poverty or one step away from losing everything,”

“Disabled people living in Dickensian levels of poverty due to austerity, rising prices of everything, cuts to universal credit,”

“For some of my Good Friends suffering poverty”

“Benefits are being cut so we are struggling with poverty... More disable people committing suicide due the extreme hardship of deprivation”

“ESA payments have not increased in line with increase in bills. £6000 cap on savings before ESA payments are reduced traps Disabled people in poverty.”

“If someone was not disabled, in another circumstance they could choose to gain employment, could save, would be better off financially, not be condemned and, forever, reliant on benefits. Benefit monies come in and go out. It is only just enough to keep the disabled people living, covering basic costs, nothing to have good health and well-being. It is a bleak life.

Disabled people are often seriously unwell, not helped or favoured to have a happy, pleasurable and valued life. It is a dark deep hole, no one would want to end up in, stressful and distressing still today living in Scottish society disabled.”

“When you have to decide between eating and heating and have to fight to get equipment you need to live and have no way to improve your life while the government cut what little money you have – it's disgusting.”

## COVID-19

### Expendable Lives

“Six months ago he became labelled as clinically extremely vulnerable because he has post polio syndrome. But before that he was not included among those shielding.”

“Many left of[f] shielding list”

“People also commented by putting people more at risk by not putting them on the 'vulnerable person' register and people not being able to get shopping. Some people couldn't queue up for food.”

“From a Carers perspective there was a variance in getting those with learning disabilities on to the vulnerable list.”

“Not being on CEV list – suggestion that you are malingering if you shielded while you weren't on it.”

“Example of only receiving notification to shield a couple of weeks before shielding officially ended.”

“I seem to be in a category where I'm not vulnerable enough to get help with essentials like food shopping, but too vulnerable to catch Covid and survive.” – Woman in Wales, living with fibromyalgia and stenosis of the spine.

“I'm on the 'vulnerable' list but not the 'extremely vulnerable' list – I am concerned about the possible effects of coronavirus on me but there is no support available with things like shopping. As a younger person with no visible disability I fear I wouldn't be allowed to use shopping hours dedicated to vulnerable people.” – Woman in London, living with ME

“We have lost both our incomes, and we were already using foodbanks before the lockdown. We can't access them now, and nobody has been in touch from the various services that were in contact with us. I am very concerned about accessing food as I cannot stand for long at all and queuing would be out of the question at supermarkets.” – Woman in Scotland, living with fibromyalgia.

“I am housebound and one of the forgotten ones. I feel very isolated, frightened, anxious, lonely, hungry, very tired, hopeless. I am hungry due to the fact I need home delivery groceries and it's a three-week wait. I am nearly down to my last scrap of food from my freezer and I don't know what I am going to do. I sleep a lot lately, very tired probably because of my high dose of medications and very little food.” – Woman in Northern Ireland, living with arthritis, complex regional pain syndrome (CRPS), dystonia, fibromyalgia, degenerative disc disease (DDD), heart condition.

“When I told the supermarkets how I rely on delivery to get basics, they responded with a script about the government’s ridiculously limited list of vulnerable groups each time. I was completely brushed aside.” – Woman in East Midlands, living with ME, polycystic ovary syndrome (PCOS), Irritable Bowel Syndrome.

“Attitudes changed around disabled people during the pandemic – suddenly being seen as people who can be 'sacrificed', who can be made to stay inside so that non-disabled people could get on with their lives.”

“Being a disabled person feels dangerous on a daily basis. I feel expendable.”

“We are considered by the government to be expendable. Second class citizens. Our lives are expensive to support, so maybe we are collateral damage. If more of us die, it will eliminate that drain on the public purse.”

“Covid we were treated as nothing, expendable and if we die we die, the uk govt do not like disabled people”

“Deaf and disabled people are subject to eugenics and seen as expendable, collateral damage and are an afterthought, if at all”

“Disabled people have been expendable during the COVID-19 pandemic, which has highlighted the general public and governments disdain when it comes to the disabled community.”

“We are regarded as expendable by the UK Government in relation to Covid, we are always third or fourth thought at best. We are regarded as a financial burden so if we die from Covid it saves the government money.”

“The Covid-19 pandemic showed us that the Government did not see disabled people as important at first. It felt like we were at the bottom of the list and had to fight for ‘our right to life’.”

“Excess deaths and pandemic – negative attitudes within the medical profession have become a lot more entrenched. – view of disabled people as expendable.”

“There is utter disregard for D&DP in every avenue of life. The response to the Covid-19 pandemic had an eugenic undercurrent”

“I was very upset to see that because I need a carer, the NHS considers me too frail for ventilation and my life not worth saving. Hard to live with this hideous, soul-crushing disease knowing the NHS doesn’t consider me worth saving. Not sure I’ll ever trust the NHS again.” – Woman in London, living with ME.

“It seemed there was little or no consideration to the survival of those vulnerable or shielding.”

“I feel the whole 'management' of the pandemic by central & local governments has been discriminatory as we have been completely overlooked.” – Woman in East Midlands, living with fibromyalgia,

Sjogren’s syndrome, osteoarthritis, spondylitis, sleep apnea, depression, disassociation disorder, PTSD.

“I feel a bit like the experiences of disabled and chronically ill people have been at once co-opted and erased. We are experts in isolation yet we've been ignored/told we are expendable.” – Woman in Scotland, living with fibromyalgia, c-PTSD, PCOS, Hashimoto's disease.

“Politicians not talking to, but talking about, disabled people (when they remember us) has been quite painful to experience. The 'oh, it only kills people with a pre-existing condition,' as though that doesn't include anyone they think is listening. It's never 'your life is valuable and we're doing all we can to support you' – it's often in the third person.” – Woman in East England, living with a thyroid condition.

“ ‘The marginalisation of people whose disabilities makes them literally the most vulnerable to a novel virus is richly ironic. I have particularly experienced this in work/educational settings: for instance where concern is expressed 'for those whose loved ones and family may be more vulnerable', rather than those who may be more vulnerable themselves.” – Woman in London, living with Behçet’s disease.

“Disabled people are held responsible for our own deaths from Covid.”

“Government continually referred to disable people in care homes and over a certain age as older rather than disabled people whereas a high percentage of people in this age group are disabled – a way of hiding the disproportionate impact on disabled people.”

“People with underlying health conditions seen as acceptable deaths in the pandemic, 60% of deaths being disabled people.”

“As of November 2020, disabled people accounted for 60% of all deaths in the UK from Covid, leaving disabled people feeling unseen, unimportant and forgotten.”

“More health inequality in system; mental health and distress. In relation to Covid, 18–34-year-old disabled people 6X more likely to die; never mind life expectancy far lower than for rest of population.”

“Recent findings by investigative journalists on people receiving homecare in their own homes – found deathrate increased enormously but only 9% due to Covid. Significant number probably due to not getting the treatment or therapy they needed – very worrying statistics.”

“During the coronavirus pandemic disabled people have been particularly hard hit. Two thirds of deaths in the UK have been disabled people or those with 'underlying health conditions'. The phrase 'underlying conditions' has been used repeatedly and in a pernicious way to suggest that disabled people's lives matter less and that 'normal' and 'fit' people need not worry about or take precautions to avoid spreading coronavirus because the only people dying are those who were already ill or disabled – 'they would have died soon anyway'.”

“local councils and the government refuse to accept responsibility for the deaths of disabled people during the pandemic.”

Ableism is rife, and it appears to me that it has become worse during the pandemic. Our lives are treated as disposable, as if we don't deserve as rich a quality of life due to our disabilities or health conditions. I hear (and read online) negative comments about disabled people daily. This ranges from things which are rude or make fun of disabled people right up to people who express views not far from eugenics e.g. that the pandemic is just killing off those that would die anyway and that it's no great loss."

"The pandemic has shown how people with "pre-existing conditions" were not valued. We are collateral damage. Many of us were not given priority vaccines (see comped chronic illnesses such as ME, MCAS, POTS, etc). Many things that were supposedly not possible before the pandemic were suddenly done for everyone (see work and study from home, events accessible from home). Many of the new access are now going back to how it was (inaccessible)."

"At the start people kept saying 'but they had an underlying condition anyway' when someone died. As if that made it ok... Then there was pressure put on disabled people to agree to DNRs if they got COVID. This really frightened me – it's as if disabled people were, and are still, acceptable collateral damage."

"The Government left disabled people and vulnerable people to die. They decided their lives were expendable. They continue, with the help of the Press, to push the narrative that current deaths are those with underlying conditions, to push this idea that these deaths were almost deserved."

"Our lives are seen as disposable. That has been clear throughout Covid. Either they give us a DNR without our consent, say that we should not live our life to the fullest or our deaths are expected and not warranted of

sympathy. Accommodations miraculously became available to abled people and now the economy is opening back up, they want to remove it. Employers continue to see us as a burden, and we are unable to progress in the same way of our peers”

## **Unlawful use of DNACPRs**

“Care home in our area that had blanket DNACPRs placed on all residents – largely autistic people – for absolutely no clinical reason”

“People were very upset that the Government allowed medics to issue DNR (do not resuscitate) orders on files of people with learning disabilities and Autism.”

“Disabled people also reported to us that they had received letters from their GP suggesting that they should agree to a Do Not Resuscitate (DNR) order against their name in the event they became unwell with Covid. This naturally caused a huge amount of concern about what would happen to disabled people who needed intensive care. Reassurances were eventually given by the NHS, but by then, confidence in the treatment disabled people would receive was damaged”

“I know of folks who's died of covid in hospital because of not receiving same treatment as none disabled/deaf people.”

“GPs were asking about Do Not Resuscitate Notices on their patients, and some patients were being advised that their care may become palliative rather than acute.”

“CQC investigation found many People with learning difficulties had “do not resuscitate” (DNR) orders included in their medical records during the second wave of the pandemic, in spite of widespread condemnation of the practice. GP surgeries had been found enacting DNR blanket policies for specific groups of people, in this case people with learning difficulties during the covid-19.”

“The National Institute for Health and Care Excellence (NICE) covid-19 critical care guidance stated that all adult COVID-19 patients should be assessed for “frailty” when admitted to hospital, and that “comorbidities and underlying health conditions” should be taken into account. CFS “frailty” scoring system consist of levels of frailty. Frailty score includes someone needing various help with day to day activities. Anyone with a Personal Assistants or anyone detained under the Mental Health Act would clearly be at disadvantaged when prioritising critical covid-19 life saving treatment. NICE revised and amended covid-19 critical care guidance after Hodge, Jones & Allen lawyers threatened with judicial review proceedings on behalf of disabled people.”

“Concerned about DNR I have been told already that I would not be ventilated. I was in hospital last week with suspected covid19 and the doc stated I would not be treated. There is no dnr in file but this was put in my discharge letter. I feel written off before I start. I hope I don't die.”

## **EU withdrawal**

### **PA/social care recruitment crisis**

“Everything is going wrong. Impossible to get personal assistants. Social care is not valued as a profession. It used to be. Horrendous now.”

“I’m having major difficulties trying to get PAs. Part of the difficulty is the pay is so bad but if I want to pay more I get less PA time.”

“There's nobody wants to go into care work. They blame it on the pandemic but I don't think it is.”

“Rise in LGBT-phobia makes it harder for LGBT service users to hire respectful/non-discriminatory PAs”

“Brexit – much more difficult employing Personal Assistants and pressure people into having to use agencies.”

“As I’m sure you are aware Brexit and loss of freedom of movement coupled with the pandemic has quickly led to a major and growing staffing crisis in social care and support for independent living for disabled people. The low pay and low status of social care work is yet a further issue affecting recruitment post- Brexit as in rural areas especially it is possible to earn much more as cleaners or in the hospitality sector.”

“The key findings [from our research] indicated that LGBTQI+ Disabled People using self-directed support reported many positives from having more choice, control and power. However there were concerns that ‘coming out’ to social care would jeopardise support. The difficulties in recruiting and retaining good PAs, the difficulties in securing support for ‘social hours’ could lead to social isolation.”

## Cost of living crisis

“People generally felt the Government didn't listen to their voices and that vital Self Advocacy projects to help to protect people's rights and disabled persons user led organisations that support people to come together as a community were closing and not being properly funded”  
“Funding for independent advocacy cut.”

“Loss of disabled people's community organisations”

“I rarely go out now and have been turned into housebound due to fear of electricity bills to recharge wheelchair, let alone not being able to afford to travel or get a coffee while out so realistically you could say I've been forced to become a recluse “I rarely go out now and have been turned into housebound due to fear of electricity bills to recharge wheelchair, let alone not being able to afford to travel or get a coffee while out so realistically you could say I've been forced to become a recluse and disappear from society which is maybe what they wish all disabled to become”

“Increasing costs of everything! Being able to afford increasing costs! Very concerned we may have to start to eat into savings to survive which will not last long! How long we can survive beyond this. How we can fend off any illnesses as a direct result of cold. 3 How we can keep our home warm enough to prevent damp and mould. How we can get our clothing and bedding dry once washed – will we have to resort to not washing clothes and bedding until Spring. Worried about social isolation – live in a rural, remote, offshore community. Also additional costs of delivery charges for essentials we can afford.”

“Supplementary Oxygen usage I use for respiratory failure, only using 4 days out of seven as I can't afford the costs. Although we do get an allowance, this has not increased with inflation and I get the same per kilowatt rate today as I got five years ago. I am using cylinders of oxygen instead of the actual machine. Its not sustainable in the long term, I expect eventually I will have to use the electrical machine or die.”

“feel much less able to go out socially which helps with my isolation and anxiety. It's kind of encouraging me to stay at home constantly and setting my mental health issues back”.

“I use a CPAP (continuous positive airway pressure) machine, every night. How am I going to afford it. My gas and electric account debit order was £54 per month. It's now £163. Without the pump, I could stop breathing. Die.”

“The stress of worrying about increasing costs is affecting my mental health, blood pressure and lack of sleep.”

“The benefits system in NI does not take cognisance of the fact that disabled people spend at least 25% more on energy, power and heat than the able-bodied. When you cannot move, you become colder. You feel the pain more. You may not be able to afford enough home heating oil to have your heating sufficiently on a timer to keep you warm. The NI Housing Executive applies unnecessarily stringent size limits on dwellings for those with disabilities – they do not take account of the additional space required for living aids and equipment; they fail to recognise that many married/living as if married couples with disabilities cannot share either a bed nor a bedroom due to the level of disability and the aids needed – yet NIHE really interrogate those in receipt of Housing Benefit

and push them further into financial difficulty. I know this from personal experience. It has been at least 10 years since NIHE uplifted their Disabled Facilities Grants costings to reflect inflation (pre-Covid)”

“The benefit cuts and increased living costs are making it impossible for disabled people to just survive. Bedroom tax, UC uplift cut, individualised reduced awards – all designed to reduce income for people who will be most adversely affected by increased heat, light, power, and fuel costs. But no-one cares.”

“I have had many weeks where I have had to choose what is best to spend my money on. Some weeks, my dog eats but I don't. Other weeks, when I need to use my car, neither of us eat for a couple of days. When my very small salary comes in, it's usually spent paying the bills, and late-payment fees from the previous month. Worrying about my bills has impacted every aspect of my life, it impacts my concentration at work, my relationships with others, my enthusiasm for exercise, and as I can't afford to eat most days that is having a huge impact on my mental health and wellbeing. I can't see this ever ending, and that scares me. Some days the only things I "eat" are my antidepressants.”

“Over the past year I have had to make sacrifices in order to pay for heating, petrol and food. For example, I have not had the heating on enough or have went to friends houses to avoid the cold. I have stopped driving as much because I can't afford petrol and have skipped meals/ selected unhealthier but cheaper versions. Financial stress weighs heavily, you cannot escape it with therapy. I feel I am destined for a life of borderline poverty. I cannot afford to buy a house or start a family. Belfast rent prices are increasing.”

“Supporting children with disabilities has become incredibly difficult, Charities have had funding cuts, and now it may be that some of those invaluable services will not survive.”

“We are on Universal Credit since my husband had to leave his job last year due to health problems. He was on basic wage so we have always struggled. Now it's worse and our mental health is quite bad.”

“I couldn't really afford the cost of filling my tank with heating oil. I sat in my home absolutely freezing during the past winter. I bought fleecy socks; fleecy snoodie; and actually had to wear gloves because I was so cold. I have asthma and arthritis and these conditions are definitely not conducive to those health conditions. In fact I developed a chest infection.”

“It's either no heat and food or heat and no food. My household bills are all behind and I am constantly terrified!”

# Annex D:

## Alternative Report from Civil Society in Northern Ireland

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# 1. Summary of Key Issues

## 1.1 Incorporation of the UNCRPD in Northern Ireland

Northern Ireland (NI) has yet to incorporate the UNCRPD into a law<sup>490</sup>.

## 1.2 Non-compliance with the UNCRPD

Northern Ireland is experiencing a severe political and economic crisis. The current situation is significantly worse than other period since introduction of the Good Friday Agreement in 1998. Northern Ireland has been without functioning political institutions since February 2022. The institutions collapsed when the Covid-19 pandemic continued to impact severely on disabled people in Northern Ireland. Since the collapse there is no mechanism through which to advance legislative changes and public services are being cut at alarming rate. The Rights of disabled people are being rolled back daily. The severity of the situation has resulted in the need to submit an Alternative Report to the Inquiry on behalf of the disabled people in Northern Ireland. The Secretary of State for Northern Ireland has failed to provide the necessary resources for public services in Northern Ireland. In doing so the Secretary of State and the Northern Ireland Office failed to address statutory duties associated with Section 75 of the Northern Ireland Act 1998<sup>491</sup>. The Secretary of State and the Northern Ireland Office (NIO) failed to undertake appropriate screening of the cumulative impacts of the proposed 2023-24 Northern Ireland Budget, contrary to its own Equality Scheme, and contrary to Section 75 and Schedule 9 of the Northern Ireland Act 1998. In doing so the Secretary of State and NIO failed to identify adverse

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<sup>490</sup> Toman, N (2022) Progress Towards the Implementation of the UNCRPD in NI. Belfast: Equality Commission

<sup>491</sup> [Northern Ireland Act \(1998\) Section 75](#) (accessed 31/07/2023)

impacts for disabled people and failed to identify mitigations to address such adverse impacts.

The Department of Finance Northern Ireland failed to undertake an Equality Impact Assessment in the appropriate way in respect of cumulative effects of the proposed 2023-24 Northern Ireland Budget, contrary to Section 75 and Schedule 9<sup>492</sup> of the Northern Ireland Act 1998, and in so doing acted ultra vires. Section 75(1)(c) provides that “a public authority shall, in carrying out its functions, have due regard to the need to promote equality of opportunity between persons with a disability and persons without”. Section 75(5) defines disability as “a physical or mental impairment which has substantial and long-term adverse effect on his ability to carry out normal day-to-day activities. This section’s definition of public authority includes the Department of Health, which is listed in Schedule 2 of the Parliamentary Commissioner Act 1967. Section 75(4) further gives effect to Schedule 9, which provides enforcement of the duties in Section 75.

Disability Inequality is a reality in our society and progress to address this is slow. Poverty, disadvantage, and barriers to employment disproportionately impact disabled people. Section 75 statutory duties are the key means available to public authorities to address inequalities and demonstrate measurable positive impact on the lives of people experiencing inequalities. The purpose of EQIAs in general is that there is a legal obligation to consider impacts on protected groups. The purpose is not merely to identify disproportionate impacts but to actively mitigate against them and ideally to seek opportunities to promote equality for these groups. Over time and in practice. This process has not been effectively progressed in Northern Ireland.

The implementation of the budget in Northern Ireland has resulted in civil servants taking decisions to cut services which disabled people in Northern Ireland are reliant on for Independent Living. These actions are in breach of

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<sup>492</sup> [Northern Ireland Act \(1998\) Schedule 9](#) (accessed 31/07/2023)

Article 19 of the UN Convention on the Rights of People with Disabilities<sup>493</sup>. The contributors to this report question the legal capacity of civil servants to take decisions normally reserved for Ministers which severely erode the rights of disabled people in Northern Ireland. Under section 3 (1) of the Northern Ireland (Executive Formation etc) Act 2022<sup>494</sup>, senior officers of Northern Ireland departments are not prevented from exercising the functions of their department if they are satisfied that it is in the public interest to do so. However, the decisions that have been taken in Northern Ireland have eroded public services and rolled back the rights of disabled people and therefore are not in the public interest. For example transport for disabled people has been reduced, reductions in spending on mobility aids, housing adaptations, restrictions in domiciliary care packages, the cessation of funding for the human rights work of Disability Action which is a DPO, closure of mental health services for young people and reductions in provision for disabled children disproportionately impact upon disabled people.

The current budget does not comply with statutory duties to target resources on the basis of objective need under Section 28E of the 1998 Act<sup>495</sup>. Justice Treacy's judgment concluded that there is a statutory provision to allocate resources on the basis of objective need<sup>496</sup>. Given the disproportionate impact of the proposed decisions on disabled people who are recognised as most at risk of poverty and deprivation. The proposals do not meet the statutory requirements of Section 28E.

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<sup>493</sup> UN General Assembly (2007): [Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly](#), Article 19 (accessed 31/07/2023).

<sup>494</sup> [Northern Ireland \(Executive Formation etc\) Act 2022 Schedule 3 \(1\)](#) (accessed 31/07/2023)

<sup>495</sup> <https://www.legislation.gov.uk/ukpga/1998/47/section/28E>

<sup>496</sup> [https://www.judiciaryni.uk/sites/judiciary/files/decisions/Committee%20on%20the%20Administration%20of%20Justice%20\(CAJ\)%20and%20Brian%20Gormally%E2%80%99s%20Application.pdf](https://www.judiciaryni.uk/sites/judiciary/files/decisions/Committee%20on%20the%20Administration%20of%20Justice%20(CAJ)%20and%20Brian%20Gormally%E2%80%99s%20Application.pdf)

There are several areas in policy, practice and legislation within NI which are non-compliant with the UNCRPD. These include amongst others, the current budget cuts, the erosion of public services, The Mental Health and Capacity Act (2016)<sup>497</sup>, inadequate protections against disability discrimination<sup>498</sup>, evidence of abuse and degrading treatment within institutional settings<sup>499</sup>, lack of access to appropriate toileting facilities, the reinstitutionalisation of disabled people<sup>500</sup> and the cessation of funding for DPOs.

### 1.3 Lack of protection of the Right to Life

The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of wave one deaths due to Covid-19 which showed that disabled people were 40% more likely to die of Covid-19<sup>501</sup>. Disabled people and their families, including parents of autistic children and carers of people with learning disabilities, are reporting that they have been asked to complete Do Not Resuscitate (DNR) orders, in case they become critically ill, with no consultation<sup>502</sup>.

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<sup>497</sup> Mental Capacity Act (NI) 2016 (accessed 31/07/2023).

<sup>498</sup> DfC (2020): [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#). p.62. (accessed 10 October 2021)

<sup>499</sup> DfC (2020): [Disability Strategy Expert Advisory Panel: Report and Recommendations](#), pp.49-54 (accessed 10 October 2021).

<sup>500</sup> PSNI (2021): [Incidents and Crimes with a Hate Motivation Recorded by the PSNI: Update 30<sup>th</sup> June 2021](#) (accessed 4 November 2021).

<sup>501</sup> NISRA (2021) [Covid-19 Deaths and Equality – Wave One](#) (accessed 2 February 2021)

<sup>502</sup> Byrne, B (ND): [How the pandemic is further alienating the disabled community](#) (accessed 21 December 2021).

## 1.4 Dignity, Choice and Control

Dignity, choice and control are of extreme importance to d/Deaf and disabled people. The key challenges raised by d/Deaf and disabled people include:

- Implementation of the Mental Capacity Act (NI);
- The application of capacity legislation for children and young people<sup>503</sup>;
- Deprivation of Liberty<sup>504</sup>;
- Inhuman and degrading treatment<sup>505</sup>;
- Use of restraint and seclusion<sup>506</sup>;
- Abuse in residential and community settings<sup>507</sup>.
- Resettlement from long-stay hospitals and assessment and treatment units<sup>508</sup>;
- Enjoyment of home and family life<sup>509</sup>;

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<sup>503</sup> Children’s Law Centre (No Date): [Written Evidence to the Ad Hoc Joint Committee on the Mental Capacity Bill](#), para 2.2. p.2 (accessed 4 Nov 2021).

<sup>504</sup> DfC (2020): [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#). p.37 (accessed 10 October 2021).

<sup>505</sup> Matthews, A (2015): [Case Study: Law Centre for Northern Ireland Litigation in Respect of Resettlement into the Community \(Muckamore Abbey\)](#) (accessed 30 December 2021).

<sup>506</sup> BASW (NI) (2021): [BASW NI policy statement concerning restraint and seclusion of children and young people in schools and educational facilities](#) (accessed 30 December 2021).

<sup>507</sup> Department of Health (2020): [Swann announces Public Inquiry into Muckamore Abbey Hospital](#) (accessed 20 October 2021).

<sup>508</sup> NIHE (2014): [The Hospital Resettlement Programme in NI after the Bamford Review](#) (accessed 10 October 2021).

<sup>509</sup> Taggart, L. (2021): [The impact of COVID-19 on people with learning disabilities in Northern Ireland: Implications for policy and practice](#), para 3.4 (accessed 21 December 2021).

- Health inequalities and mortality rates<sup>510</sup>;

## 1.5 Continued Lack of Protection Against Disability Discrimination

There have been repeated concerns raised that protection for people with disabilities against discrimination in NI has fallen behind GB<sup>511</sup>.

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<sup>510</sup> NISRA (2021) [Covid-19 Deaths and Equality – Wave One](#) (accessed 2 February 2021)

<sup>511</sup> Toman, N (2022) [Progress Towards the Implementation of the UNCRPD in NI](#). Belfast: Equality Commission (accessed 12 March 2022).

## **2. Introduction**

### **2.1 About Us**

Disability Action is the largest disabled person led and pan-disability organisation in the UK located NI. We provide services to and advocate for the rights of d/Deaf and disabled people.

### **2.2 The Process**

1 in 4 people in Northern Ireland are disabled people. Disability Action engaged with 1849 disabled people in the production of the report and 335 member organisations.

Desktop research was carried out into relevant programmes and policies in NI and reference made to previous research.

### **2.3 The Scope of the Report**

This report only relates to Northern Ireland (NI).

### **2.4 Purpose of the Report**

This report provides information on the implementation of Articles 19, 27 and 28 by the Northern Ireland Executive and Assembly and the UK Government (UKG) since publication in November 2016 of the findings and recommendations from the Committee's inquiry under article 6 of the Optional Protocol to the Convention on the Rights of Disabled People.

## 2.5 Social and Human Rights Model of Disability

This report has been developed utilising the human rights model of disability, taking account of the social model of disability<sup>512</sup>. The human rights model focuses on the inherent dignity of the human being and places the individual centre stage in all decisions. Most importantly, it recognises the role which society plays in disability<sup>513</sup>. The social model of disability asserts that disability is a form of oppression and socially created disadvantage and marginalisation of people on the basis of disability or impairment. Disability is therefore considered as a socially produced injustice which is possible to challenge and address through social change<sup>514</sup>. Both models recognise that the challenges of disability are societal factors which are external to the individual. The human rights model both builds on and complements the social model. Both models are valuable tools towards achieving equality, participation, inclusion, quality of life and dignity for d/Deaf and disabled people. For some purposes, including the monitoring of the State party's efforts to implement the UNCRPD<sup>515</sup>, the human

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<sup>512</sup> Oliver, M., (1981): [A new model of the social work role in relation to disability](#), pp.19-32, (accessed 1 January 2022).

<sup>513</sup> Quinn, G. and Degener, T. (2002): [The moral authority for change: human rights values and the worldwide process of disability reform](#), Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability, pp.9-18 New York, Geneva: United Nations (accessed 1 January 2002).

<sup>514</sup> Lawson, A. and Beckett, A.E. (2020): [The social and human rights models of disability: towards a complementarity thesis](#), *The International Journal of Human Rights*, 25 (2), pp.348-379.

<sup>515</sup> UN General Assembly (2007): [Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly](#), 24 January 2007, A/RES/61/106 (accessed 4 November 2021).

rights model is more appropriate. The social model plays an essential role in the identification of barriers and the development of appropriate solutions<sup>516</sup>.

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<sup>516</sup> Lawson, A., Beckett, A.E. (2020): [The social and human rights models of disability: towards a complementarity thesis](#). *The International Journal of Human Rights*, 25 (2), pp.348-379.

## 3. Over-view since 2016

### 3.1 Failure to implement the Committee's Recommendations

Disabled people are overwhelmingly of the view that the Committee's recommendations have not been implemented in NI.

The rights of disabled people have significantly eroded since 2016. The Northern Ireland Executive and Assembly has collapsed twice within the reporting period. Northern Ireland is experiencing political, economic and public finance crisis. There has been limited positive progress to advance the rights of disabled people, the abuse and reinstitutionalisation of disabled people is increasing and public services have eroded. NI has experienced the Covid-19 pandemic during this period and continues to experience a cost of living emergency, a health emergency and a housing emergency all of which has seriously eroded the rights of disabled people. Funding for the human rights work of Disability Action, Human Rights Organisations and services to disabled people has been removed with accountability and in the absence of functioning political and legislative institutions.

There has been limited progress to implement a Bill of Rights for Northern Ireland which is a commitment under the Good Friday Agreement. A Bill of Rights for Northern Ireland would significantly advance the rights of disabled people.

There is continued and significant retrogression of the rights of disabled people in relation to the areas covered by the special inquiry.

#### **Suggested questions**

1. What action will the Westminster Government take as co-guarantors of the Good Friday Agreement to ensure that the political institutions are re-

established on a sustainable footing to ensure that there are mechanisms in place to advance legislation in Northern Ireland?

2. What actions will the State take to ensure that the state in Northern Ireland has access to appropriate resources to deliver public services?
3. What actions will the State take to ensure that the rights of disabled people are protected?
4. What measures will the State in Northern Ireland take to ensure that the UNCRPD is incorporated into law?
5. What actions will the state take to ensure a Bill of Rights is enacted in Northern Ireland?

## 3.2 Article 19

### 3.2.1 Health and Social Care

Social care has been eroded in NI. adverse impact on Disabled People's right to independent living. In common with other areas of healthcare, social care has been impacted negatively by short-term budgets.

Community and voluntary providers are at the forefront of prevention and early intervention<sup>517</sup>. Despite this the Department of Health has withdrawn funding from 62 organisations<sup>518</sup>. The cessation of this funding will place additional pressure on the health and social care system.

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<sup>517</sup> <https://publications.parliament.uk/pa/cm201919/cmselect/cmniaf/300/30007.htm> para 91

<sup>518</sup> <https://www.newsletter.co.uk/health/department-of-health-funding-cuts-to-eviscerate-community-groups-throughout-province-4155869>

Northern Ireland is the midst of a health emergency arising from spiralling costs and the absence of Ministerial decision making and accountability. During the winter months patients were advised to discharge to care homes due to a shortage of care packages and the high volume of people in hospital. These actions have re-institutionalised disabled people<sup>519</sup>. The Department of Health have proposed restricting access to domiciliary care because of the public finance crisis. This will lead to the re-institutionalisation of disabled people and further erode the health service.

Legislation required for the reform of Adult Social Care has not proceeded due to ongoing political crisis. Access to services has been reduced in the context of the current public finance crisis. Austerity has led to the collapse of health and social care in NI. This has been further compounded by the ongoing political and financial crisis in NI. Reductions in access to domiciliary care, Personal Independence Payment, and the cessation of the independent living fund have forced disabled people into institutions.

**What action will the State in NI take to advance the reform of Adult Social Care ensuring that that the right to independent living is protected in legislation and that funding is made available to advance improvements co-designed with disabled people?**

### 3.2.2 The Independent Living Fund

The closure of the Independent Living Fund to new applicants has limited d/Deaf and disabled people's choice and control<sup>520</sup> in Northern

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<sup>519</sup> <https://www.belfasttelegraph.co.uk/news/northern-ireland/patients-urged-to-move-into-care-homes-to-address-hospitals-crisis/41085906.html>

<sup>520</sup> DfC (2020): [Disability Strategy and Expert Advisory Panel: Report and Recommendations](#) p.34 (accessed 10 October 2021).

Ireland. The roll out of Self-Directed Support as a model to promote choice and control has been limited<sup>521</sup>. Access to appropriate social care packages and accessible housing have been recognised as the cornerstones of independent living<sup>522</sup>. The demand for social care is increasing and access to funding is decreasing<sup>523</sup>. Disability Action recently conducted a small research study on Adult Social Care<sup>524</sup>. There is an absence of information regarding the extent to which the needs of d/Deaf and disabled people with substantive needs and who are not in receipt of the Independent Living Fund payments are met by Self-Directed Support (SDS) and Direct Payment Provisions<sup>525</sup>. Direct Payments do not fund many of the activities funded by the Independent Living Fund as the emphasis is upon addressing social care needs rather than promoting independence meaning that those in receipt have access to less support and have less control<sup>526</sup>. The potential direct payments to promote Independent Living has been hampered by cost savings to social care budgets<sup>527</sup>.

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<sup>521</sup> Ibid, p.38.

<sup>522</sup> UKIM (2018): [Progress on disability rights in the United Kingdom](#), p.12 (accessed 10 October 2021).

<sup>523</sup> British Medical Association (2020): [Social care in Northern Ireland](#) (accessed 21 February 2022).

<sup>524</sup> McDonald, A. (2017): Is Adult Social Care Legislation and Policy Compliant with Article 19 of UNCRPD? Belfast: Disability Action.

<sup>525</sup> UKIM (2018): [Progress on disability rights in the United Kingdom](#), p.12 (accessed 10 October 2021).

<sup>526</sup> IMNI (2017): [United Nations Convention on the Rights of Persons with Disabilities Jurisdictional 'Parallel' Report on Implementation in Northern Ireland: Working Paper](#), p.42 (accessed 2 November 2021).

<sup>527</sup> Pearson, C. and Ridley, J. (2016): Is personalisation the right plan at the wrong time? Re-thinking cash-for-care in an age of austerity, *Social Policy and Administration*, 51 (7). pp. 1042-1059.

What actions will the State take to ensure that there is investment in health and social care?

The Independent Living Fund has not been reopened as was promised to disabled people due to the absence of Ministers and the lack of functional political and legislative institutions in Northern Ireland.

### **Suggested question**

**What actions will the State take to reopen the Independent Living Fund?**

### **3.2.3 Mental Health Legislation**

Mental health legislation continues to authorise substitute decision-making, detention in psychiatric institutions, involuntary treatment and the use of community treatment orders.

The Mental Capacity Act (2016) is non-compliant with the UNCRPD. The MCA Act (2016) provides for determinations of unfitness to plead and the defence of insanity which is representative of disability discrimination in context of the UNCRPD<sup>528</sup>. The Mental Health (NI) Order (1986)<sup>529</sup> provides for involuntary treatment of ‘mental disorder’, which is defined as ‘mental illness, mental handicap and any other disorder or disability of mind’ (MHO, Article 3(1))<sup>530</sup>.

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<sup>528</sup> Committee on the Rights of Persons with Disabilities (2014): General Comment No.1: Article 12: Equal recognition before the law. UN: CRPD/C/GC/1

<sup>529</sup> [The Mental Health \(Northern Ireland\) Order 1986 9](#) (accessed 12 March 2022)

<sup>530</sup> The MHO is accompanied by a short Code of Practice, and what is known as the [GAIN Guidelines](#), which set out detailed information about the provision of mental health care in line with the MHO (accessed 12 March 2022).

## Suggested question

**What actions will the State take to ensure that Mental Health and Capacity Legislation is UNCRPD compliant?**

### 3.2.4 Abuse Scandals

The Health emergency and the political and public finance crisis has resulted in the re-institutionalisation of disabled people. The potential for abuse is greater within institutional settings as demonstrated by the launch of a Public Investigation into events at Muckamore Abbey Hospital<sup>531</sup> and the Older Person's Commissioner's report on Dunmurry Manor<sup>532</sup> both of which include evidence of violence against and the abuse of d/Deaf and disabled people. The Health Minister Robin Swann pledged to bring forward a new Adult Safeguarding Bill for Northern Ireland, to help protect disabled people<sup>533</sup>. This has not progressed due to the absence of functioning political institutions in Northern Ireland.

There is currently no legislative and decision making framework through which to advance the findings of the Muckamore Inquiry in an ethical and accountable manner.

Disability Action are aware of cases in which disabled people have been abused and in spite of evidence including cctv footage , cases have not proceeded to court due to the Public Prosecution Service questioning whether a person who is non-speaking can articulate

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<sup>531</sup> DoH (2020): [Muckamore Abbey Hospital – Public Inquiry](#) (accessed 2 November 2021).

<sup>532</sup> COPNI (2020): [Commissioner for Older People concludes his Home Truths investigation into Dunmurry Manor Care Home](#) (accessed 15 December 2021).

<sup>533</sup> DoH (2020): [Minister announces plans for Adult Safeguarding Bill for Northern Ireland](#) (accessed 15 December 2021).

impact. These cases have occurred within institutional and health care settings.

### **Suggested questions**

**What actions will be taken by the State in Northern Ireland to ensure that adult safeguarding legislation is developed in partnership with disabled people and disabled people's organisations to ensure that all interventions are based on informed consent?**

**What measures will be taken by the State in Northern Ireland to ensure that disabled people have access to justice in cases of alleged abuse?**

### **3.2.5 Housing**

Research undertaken by Disability Action on behalf of the Equality Commission demonstrates that 8 out of 10 disabled people believe housing is inaccessible to them. Northern Ireland is experiencing a housing emergency – which is having a severe impact on disabled people. 52% of the social housing waiting list are older people, disabled people and people experiencing mental health challenges

The most recent published data from the Department for Communities demonstrates that there are only 1,111 accessible social homes in the region, yet according to the most recent census<sup>1</sup> in 4 people in Northern Ireland are disabled people. There is a significant undersupply of accessible housing in the region. Disabled people are trapped in unsuitable housing due to this housing shortage.

Disabled people are trapped in unsafe and undignified housing. Through our case work we know that disabled people have faced challenges in having their doors widened and ramps fitted. We have worked with disabled people who have been unable to access

dignified toileting in their home because they cannot access the stairs to use the toilet. The conditions in which they are living are devastating leading to declining physical and mental health. Living in inappropriate housing has negative impacts on quality of life, and physical and mental health.

Adaptation grants are available, but they are means tested and the process for applying is complicated- it is our position that resources for adaptation should be available based on need and not income. If a family receives child benefit for the young person- then the test of resources is not applied. Grants are only paid once the work is completed which presents a significant barrier to be done.

Disabled residents in Northern Ireland, in the private housing sector, whose adaptations were completed in 2020/21, and the first seven months of 2021/22 (up to 31 October 2021), waited more than three years on average for them to be finished.

Disabled residents in the private housing sector have waited between nine and 20 months on average for home adaptations to be completed once they had received an 'approval of application' from the Housing Executive in 2020/21.

The current political crisis has resulted in a series a lack of accountability which coupled with a public finance crisis has resulted in a series of decisions which adversely impact upon disabled people. With respect to housing it has been proposed that the Northern Ireland Housing Executive Budget will be reduced. Reductions to the NIHE budget by DfC will lead to longer delays in housing adaptations, and increased risk of homelessness all of which disproportionately impact upon disabled people. There is a significant deficit in the provision of accessible social homes. The reduction in building will further reduce opportunities for disabled people to access an accessible home. The lack of access to housing, housing adaptations

and housing support will lead to the reinstitutionalisation of disabled people which will increase spending within the Department of Health. The proposed decision by DfC to reduce the NIHE budget<sup>534</sup> requires a cross Departmental cumulative assessment.

### **Suggested question**

**What actions will be State take to ensure that the current political crisis does not adversely impact on disabled people through the reduction in the building of accessible social homes, reductions in housing support and housing adaptations?**

## **3.2.6 Transport**

8 out of 10 disabled people report that transport is inaccessible to them. Disability Action Transport Service has been cut by 5%. Reductions in public transport have been proposed alongside reductions in the concessionary fares scheme. There is a shortage of wheelchair accessible taxis. The combined result is that disabled people are living under curfew with limited access to accessible transport.

### **Suggested Question**

**What action will the State take to ensure that there is investment in transport options for disabled people?**

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<sup>534</sup> <https://www.communities-ni.gov.uk/sites/default/files/consultations/communities/dfc-budget-2023-24-egia.pdf> p.21

### 3.3 Article 27

Barriers to employment for disabled people have increased in the context of the Covid-19 pandemic, the Cost of Living Emergency and the ending of access to the European Social Fund because of Brexit. Northern Ireland: In 2020 the disability employment rate gap in Northern Ireland was 42.2 % compared to 27.9 % for the whole of the UK. Since 2014, the disability employment gap has consistently been higher in Northern Ireland than the rest of the UK<sup>535</sup>. Figures for 2022 demonstrate that disabled people in Northern Ireland earn £1.90 per hour less than non-disabled people, meaning that disabled people earn £3458 less per year than non-disabled people. Therefore, the disability pay gap in Northern Ireland is 18%. Disabled women earn £1.70 per hour less than disabled men<sup>536</sup>. In addition:

- a higher proportion of d/Deaf and disabled people are in part time work. Part-time work, particularly in the private sector is paid less per hour than full-time work.
- d/Deaf and disabled people are overrepresented in lower paid jobs including caring and leisure, sales, customer services, and other services;
- d/Deaf and disabled people are under-represented in senior and managerial roles.
- some d/Deaf and disabled people leave education earlier than non-disabled people; when d/Deaf and disabled people have the same qualifications the pay gap persists<sup>537</sup>.

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<sup>535</sup> <https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-disability-within-northern-ireland-labour-market-2022.pdf>, para 5.1 page 29

<sup>536</sup> <https://www.tuc.org.uk/news/non-disabled-workers-paid-17-more-disabled-peers-tuc>

<sup>537</sup> TUC (2020): [Disability pay and employment gaps 2019](#) (accessed 1 February 2022).

- when d/Deaf and disabled people have the same qualifications the pay gap persists<sup>538</sup>.

Trade Union Congress (TUC) assert that the Disability Pay Gap is linked to unlawful discrimination, structural barriers, and negative attitudes<sup>539</sup>.

ESF has been the primary source of funding for employment projects for d/Deaf and disabled people in NI. The funding will cease in March 2022. Finance Minister Conor Murphy allocated £26.5mn of Covid-19 funding to extend the ESF programme until the end of March 2023. This programme has now ended. The UK Shared Prosperity Programme offers £20mn funding less than ESF leaving the region at severe disadvantage.

The current equality framework in Northern Ireland is deeply inadequate. The Equality Act 2010 is also still not applicable in Northern Ireland despite the previous recommendation of the committee.

### **Suggested questions**

**What actions will the State Party take in NI to ensure mandatory pay gap reporting and the introduction of action plans to address the disability pay gap?**

**What actions will the State take to address the Disability Employment Gap in Northern Ireland?**

**What steps are being taken to address challenges in access to employment by disabled people and that action is taken to introduce stronger equality legislation to ensure that citizens in NI have the same protections as their counterparts in the UK and Ireland.**

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<sup>538</sup> TUC (2020): [Disability pay and employment gaps 2019](#) (accessed 1 February 2022).

<sup>539</sup> TUC (2020): [Disability pay and employment gaps 2020](#) (accessed 1 February 2022).

## 3.4 Article 28

### 3.4.1 Poverty

Northern Ireland: d/Deaf and disabled children and their families are more likely to live in poverty than their non-disabled counterparts<sup>540</sup>. d/Deaf and disabled people are 50% more likely to live in poverty and disadvantage than those who do not have a long-standing illness<sup>541</sup>. Households with one or more d/Deaf and disabled members faced large and disproportionately negative impacts from tax and benefit changes made between 2010 and 2018<sup>542</sup>. 78% of d/Deaf and disabled people not in receipt of disability social security benefits come from households experiencing the highest levels of deprivation. According to the Trussell Trust Foodbank Network, which operates 36 foodbanks across Northern Ireland, more than 62% of working age d/Deaf and disabled people are referred to their network for support<sup>543</sup>. 23% of households with a disability were losing more than a quarter of their income on repaying debt or loans, compared to 14% among households not affected by disability whilst 41% of d/Deaf and disabled people were in debt to the UK Department of Work and Pensions (DWP)<sup>544</sup>. The Trussell Trust also found that even if some people were successful in applying for and receiving disability benefits such as DLA and PIP, for many it was not enough to prevent hardship

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<sup>540</sup> Child Poverty Alliance (2014): [Beneath the Surface](#) (accessed 4 November 2021).

<sup>541</sup> UKIM (2018): [Progress on disability rights in the United Kingdom](#). p.21 (accessed 10 October 2021).

<sup>542</sup> EHRC (2020): [The cumulative impact of tax and welfare reforms](#), p.15 (accessed 3 November 2021).

<sup>543</sup> BBC (2021): [Coronavirus: Food bank need for NI children 'at historic level'](#), (accessed 2 January 2022).

<sup>544</sup> The Trussell Trust (2021): [The State of Hunger: it's not right that disabled people are being forced to turn to food banks](#) (accessed 2 January 2020).

and material deprivation in many households indicating that disability benefits, for those fortunate enough to meet the threshold for entitlement, was not sufficient to meet the extra costs associated with disability and ill health<sup>545</sup>. Disabled People have been unable to access cost of living payments issued by the Department for Communities.

The political crisis has halted the development of the Anti-Poverty Strategy. There is a public funding crisis which is eroding the very fabric of Northern Ireland society and plunging disabled people further into poverty and disadvantage.

Disabled people are making impossible choices between eating and breathing without intervention<sup>546</sup>.

### **Suggested Question**

**What actions will the State take to ensure that disabled people have access to emergency relief payments on an equal basis with others?**

**What actions will the State take to address the underlying causes of poverty?**

### **3.4.2 Social Security**

Social Security continues to be inadequate for disabled people. There have been no positive actions taken to challenge negative and harmful perceptions of disabled people.

There is considerable evidence which demonstrates the adverse impact of welfare reform on the right of d/Deaf and disabled people to

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<sup>545</sup> Ibid.

<sup>546</sup> <https://www.bbc.co.uk/news/uk-northern-ireland-62956362>

live independently and to an adequate standard of living and social security<sup>547</sup>:

- families, where someone has a disability, have lost an average of £2,000 per year because of changes to disability related benefits<sup>548</sup>;
- households with at least one d/Deaf and disabled adult and/or a d/Deaf and disabled child will lose over £6,500 a year (over 13% of their net income)<sup>549</sup>;
- those d/Deaf and disabled people claiming Employment Support Allowance and Universal Credit assessed as being in the work-related activity group in receipt of both benefits through the work capability assessment have had their income reduced by £30 per week losing their disability premiums within both benefits<sup>550</sup>;
- there is also some evidence to suggest that d/Deaf and disabled people have not only fallen further into poverty but also lost their lives because of welfare reform changes<sup>551</sup>;

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<sup>547</sup> UKIM (2018): [Progress on disability rights in the United Kingdom](#), p.21 (accessed 10 October 2021).

<sup>548</sup> Northern Ireland Human Rights Commission (November 2019): [Cumulative Impact Assessment \(CIA\) of the Impact by Reforms to the Tax and Social Security System in Northern Ireland](#), see Section Heading 4.2 Impact by Disability Status of Adults and Children in the Household, pages 53-59 (accessed 5 November 2021).

<sup>549</sup> Ibid, p.88.

<sup>550</sup> UK Parliament (2019): [Ten Years of the Work Capability Assessment](#) (accessed 18 December 2021).

<sup>551</sup> The Guardian (2020): [Errol Graham is the latest victim of a cruel system – we need a culture shift](#) (accessed 18 December 2021).

The evidence outlined above demonstrates that disabled people and families do not receive enough from social security to meet their needs and have instead to rely on food banks, miss meals and face considerable challenges in running lifesaving equipment. Disability Action case work includes cases in which disabled people have referenced rationing access to life saving machinery due to increasing energy costs.

The Commission on Social Security<sup>552</sup> – led by experts by experience – argues that the current working-age benefits system should be replaced by a system that is no longer “guided by stereotypes and myths about Disabled people and people in poverty”. The Plan for a Decent Social Security System calls for the following transformational changes:

- Everyone would be treated with dignity and respect
- Nobody would ever have less than half the minimum wage currently £163.50 a week – to live on, because of the Guaranteed Decent Income (GDI)
- The Joseph Rowntree Foundation Minimum Income Standards for what amount of money is needed for an acceptable standard of living would be ensured
- Child benefit of £50 per child each week
- The importance of other factors in providing social security – good jobs, housing, childcare and so on – would be recognised and acted on.

Benefits and tax credits were increased by 3.1% in the annual uprating. This was not in line with inflation. Therefore, in real terms benefits

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<sup>552</sup> <https://www.commissiononsocialsecurity.org/>

have been cut. This follows the £20 a week drop in Universal Credit last October; itself the most dramatic single cut in welfare provision for a generation.

Substantial numbers of disabled people have lost income through the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP).

Concerns raised by the UN Extreme Poverty Rapporteur regarding the roll out of Universal Credit were dismissed.<sup>553</sup> A legal challenge taken by two disabled men who had lost £180 per month after being moved to UC won compensation for others similarly affected but there remains no SDP/EDP for new claimants.<sup>554</sup>

Benefits assessments continue to cause widespread distress among DDP, stress on our families/support networks and strain on support services. The issues are the same that we have been reporting for over a decade.

### **Suggested Question**

**What steps will the State take to ensure that disabled people are afforded an adequate standard of living through the social security system?**

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<sup>553</sup> [Alston, P. \(2018\). \*Statement on Visit to the United Kingdom\*. \[online\].](#)

<sup>554</sup> DWP resisted fully compensating DDP for their losses resulting in a further three high court hearings, all which WeG lost. The ruling will affect up to 50,000 people and will involve sums of up to £150 million over a six-year period to put right. [Leigh Day \(2022\). \*Severely disabled benefits claimants win legal challenge over loss of income caused by move on to Universal Credit\*. \[press release\] 21 January.](#)

### 3.5 Disability Stereotypes

The State has failed to address the Committee's recommendation to combat negative stereotypes of disabled people. Incidents of bullying hate speech and hate crime against d/Deaf and disabled children continue to increase. The cost of living emergency has resulted in a deterioration in attitudes towards disabled people in receipt of benefits, reminiscent of those seen when the Committee conducted its Inquiry in 2016.<sup>555</sup>

#### Suggested Question

**What actions will the State take to challenge negative stereotypes of disabled people?**

**What actions will the State take to ensure that there is an enforceable legal framework through which to address disability hate crime?**

### 3.6 Article 33

There is no official collection of appropriate data related to the lived experience of deaf and deaf and disabled people or the impact of changes in legislation with respect to disability in Northern Ireland<sup>556</sup>. There is at present no co-ordinated strategy for the incorporation of the UNCRPD into law<sup>557</sup> and progress is difficult to monitor.

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<sup>555</sup> [A decade after the Tories demonised disabled people on benefits, it's happening again | Frances Ryan | The Guardian](#); [Broadcaster's silence over 'rabblrouser' tweet on disability benefits – Disability News Service](#); [Exactly how much of your salary bankrolls Britain's benefits system \(telegraph.co.uk\)](#); [When will the Tories face up to Britain's benefits scandal? | The Spectator](#)

<sup>556</sup> DFC (2020) [Disability Expert Panel Report and Recommendations](#) p.25 (accessed 15 December 2021)

<sup>557</sup> DFC (2020) [Disability Expert Panel Report and Recommendations](#) p.13 (accessed 15 December 2021)

## **Suggested question**

**What action will the State take to ensure the full incorporation of the UNCRPD which includes a strategy for implementation and monitoring?**

**How will the State develop indicators that will relate to the UNCRPD and be comparable against other devolved nations and internationally (and be inclusive of d/Deaf and disabled children and adults with disabilities)?**

## 4. New Issues

### 4.1 Brexit

Brexit has stimulated the collapse of the political and legislative institutions in Northern Ireland. This has resulted in a complete hiatus in the development of legislation and has stimulated a public finance crisis which is severely undermining the rights of disabled people.

Brexit has created recruitment challenges in health and social care. Disabled people living in their own homes now face even greater barriers to recruiting Personal Assistants (PAs).<sup>558 559</sup>

#### Suggested Question

**What actions will the state take to ensure that Brexit does not undermine the rights of disabled people?**

### 4.2 Covid-19

Disability inequality was becoming entrenched before the pandemic.<sup>560</sup> The impacts of the pandemic both exacerbated and were exacerbated by that

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<sup>558</sup> This was an issue on which we received numerous submissions in our consultation for the 2022 shadow report.

<sup>559</sup> The National Care Forum warned that the sector is facing the “most acute recruitment and retention crisis” in its history, with more than 110,000 vacancies. [Delahunty, \(2021\). Care sector facing 'most acute recruitment and retention crisis' in its history, not-for-profit organisations warn. \*Thirdsector.com\*, \[online\] 29 September.](#)

<sup>560</sup> In 2018 the EHRC warned that “Britain’s most at-risk groups of people are in danger of being forgotten and becoming trapped in disadvantage...This inequality risks becoming entrenched for generations to come, creating a two-speed society where these groups are left behind in the journey towards a fair and equal country.” These groups consist of Disabled

existing inequality. Northern Ireland was not prepared for the pandemic. The degree to which the emergency response of the Executive to the Covid-19 crisis included people with disabilities and addressed their needs has been called into question by d/Deaf and disabled people and by the Equality Commission for Northern Ireland<sup>561</sup>. Initial guidance from government agencies was not attuned to the needs of persons with learning disabilities and their living situations; particularly for those in supported living arrangements rather than residential homes. The guidance from different agencies was contradictory and had not been developed through consultation with organisations and personnel with the necessary expertise. Revised guidance has been made available, but a lack of consultation remains an issue beyond Covid-19<sup>562</sup>. The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of wave one deaths due to Covid-19 which showed that disabled people were 40% more likely to die of Covid-19<sup>563</sup>.

There are concerns regarding the inappropriate use of Do Not Resuscitate Orders<sup>564</sup>. Disabled people were over-represented among COVID-related

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people, some ethnic minorities, and children from poorer backgrounds for whom "Prospects... have worsened in many areas of life." [Equality and Human Rights Commission \[EHRC\], \(2018\) \*Is Britain Fairer? The state of equality and human rights in Britain.\* \[online\], p.5.](#)

<sup>561</sup> ECNI (2020): [People with disabilities must not be left behind by response to COVID-19](#) (accessed 5 November 2021).

<sup>562</sup> ARC (NI) (2020): [A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland](#), p.8 (accessed 5 November 2021).

<sup>563</sup> NISRA (2021) [Covid-19 Deaths and Equality – Wave One](#) (accessed 2 February 2021)

<sup>564</sup> BBC (2021): [People with learning disabilities 'living a nightmare'](#) (accessed 28 December 2021.) This article includes Amanda Paul's contribution to the Disabled People's Parliament in which Amanda recounts her own experience with respect to Do Not Resuscitate Orders.

deaths<sup>565</sup> even accounting for age and health factors. Analysis by ONS identifies poverty as a key factor within this as well as care home residency.<sup>566</sup>

Disabled workers were over-represented among redundancies during the pandemic. From July to November 2020, 21.1 per thousand disabled workers were made redundant compared to 13.0 per thousand who are non-disabled.<sup>567</sup> Disabled people faced long delays following requests adjustments and a range of other issues with Access to Work after home working began during lockdown.<sup>568</sup> Workers experiencing Long Covid have faced employment discrimination.<sup>569</sup> One in seven survey respondents lost their job because of reasons connected to Long Covid.<sup>570</sup>

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<sup>565</sup> Official figures record that disabled people accounted for nearly 60% of COVID-related deaths. The true proportion is likely to be higher: disabled people made up 17.2% of the study population which is lower than the 22% of disabled people within the UK population. [Office for National Statistics \[ONS\], \(2021\). Updated estimates of coronavirus \(COVID-19\) related deaths by disability status, England: 24 January to 20 November 2020. \[online\] 11 February.](#)

<sup>566</sup> [Office for National Statistics \[ONS\], \(2020\). Coronavirus \(COVID-19\) related deaths by disability status, England and Wales: 2 March to 14 July 2020. \[online\] 18 September.](#) “This means a sizeable part of the difference in COVID-19 mortality between disabled and non-disabled groups is explained by the different circumstances in which members of those groups are known to live, such as domains of socio-economic disadvantage.

<sup>567</sup> [ONS \(2021\). Coronavirus and redundancies in the UK labour market: September to November 2020. \[online\]](#)

<sup>568</sup> Prompting Inclusion London to write to the Minister for Disabled People urging action to be taken to protect DDP’s jobs. [Inclusion London \(2020\). Fix problems with Access to Work to protect Disabled people’s jobs. Inclusionlondon.org.uk, \[online\] 5 May](#)

<sup>569</sup> Given numbers experiencing this, this is a big issue. As of March 2023, an estimated 1.9 million people were experiencing self-reported Long Covid in the UK. [ONS \(2023\). Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK: 30 March 2023. \[online\]](#)

<sup>570</sup> [TUC and Long Covid Support \(2023\). Workers’ experiences of Long Covid. \[online\] March](#)

The pandemic saw a return to purely medical understanding of risk and “vulnerability” leaving millions at risk from non-medical factors linked to self-isolating that were not considered in planning.<sup>571</sup>

In March 2020, a temporary pandemic lift to UC of £20 per week was introduced. This was not applied to over 2.2 million legacy benefit claimants, three quarters of whom are disabled. Many had significantly increased expenditures due to COVID-19.<sup>572</sup> The explanation was that the uplift was for people who work.<sup>573</sup> This statement suggests that disabled people are not valid

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<sup>571</sup> [TourettesHero, \(2020\). Understanding the Risks. \[online\].](#)

<sup>572</sup> For example: for the purchase of Personal Protective Equipment for themselves and their Personal Assistants/support workers, through increased energy costs and due to online delivery fees. In a survey of 1,800 benefit claimants more than three quarters (78%) said their financial situation was ‘worse’ compared to at the start of the pandemic; half (52%) were spending ‘significantly more’ on household bills and utilities than they were before the pandemic; 67% were struggling to eat a balanced diet, 67% were struggling to pay bills and just under half (46%) were falling behind on rent or mortgage payments . Personal testimonies shared by legacy benefit claimants included experiences from families unable to wash or do laundry regularly. Disability Benefits Consortium (2021). *The Millions Missing Out*. [press release] 26 August. Available at: <https://disabilitybenefitsconsortium.com/2021/08/26/test-post/> Accessed on: 15.03.22.

Disabled People Against Cuts (2021). *#20More4All – Why the £20 per week uplift to Universal Credit must be applied to legacy benefits: testimonies, stats & facts*. [online]. Available at: <https://dpac.uk.net/2021/03/20more4all-testimonies-stats-facts/>. Accessed on: 15.03.22

<sup>573</sup> Chancellor of the Exchequer explained in a televised interview that the uplift was intended for those adjusting to loss of income through losing their jobs due to the pandemic. He said: “The original rationale for doing the temporary uplift in universal credit was to help those on low incomes. People who were in work but whose incomes were going to be affected by the crisis. It is universal credit and working tax credit that are the benefits that capture the vast, vast, vast majority if not all of those people. The legacy benefits don't do that.” *The Martin Lewis Money Show* (2021). [TV programme] ITV, 5 March: 20:30; Money Saving Expert (2021). *Martin Lewis grills Chancellor Rishi Sunak on self-employed income support, stamp duty, benefits help & more*. *moneysavingexpert.com*, [online] 5 March. Available at: <https://www.moneysavingexpert.com/news/2021/03/martin-lewis-interviews-chancellor-rishi-sunak---the-key-questio/> Accessed on: 15.03.22

part of the workforce. This fuelled a view among the UK Government does not value their lives.<sup>574</sup>

Even after the uplift, UC represented just 43.4% of the minimum income required for a decent standard of living.<sup>575</sup> The UK Government removed the uplift on 30 September 2021.<sup>576</sup>

## Suggested Questions

**What specific measures are being taken by the State to ensure that any requirements to ensure the full protection of the right to life for all people with d/Deaf and disabled people are being addressed?**

**What actions will the state take to ensure that disabled people are fully involved in emergency planning?**

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<sup>574</sup> Direct references to disability hostility and feelings that the Westminster Government does not value Deaf and Disabled people's lives: CBCE6, CBCE8, CBCE9, CBCE13, CBCE14, CBCE27, CBCE28, DDPO42, D.DP29, FG2, SR15, SR22, SR100, SR114, SR134, SR145, SR148, SR180, SR182, SR188, SR190, SR208, SR224, SR258, SR266, SR284, SR289, SR293, SR327, SR333

<sup>575</sup> Without the uplift, UC is just 33.9% of the amount needed for a decent standard of living. without Joseph Rowntree Foundation (2021). *Planned cuts to Universal Credit will hit incomes of millions of households unable to afford a minimum living standard*. [press release] 14 July. Available at: <https://www.jrf.org.uk/press/planned-cuts-universal-credit-will-hit-incomes-millions-households-unable-afford-minimum> Accessed on: 15.03.22

<sup>576</sup> Despite widespread opposition including from senior Conservatives and former Secretaries of State for Work and Pensions. Jones, H. (2021). Six ex Tory ministers call for Universal Credit increase to become permanent. *Metro*, 4 July. Available at: <https://metro.co.uk/2021/07/04/six-ex-tory-ministers-call-for-universal-credit-increase-to-become-permanent-14871676/> Accessed on: 15.03.22

### 4.3 Disabled Women

Disabled women have experienced severe poverty, abuse and exploitation. This has increased since 2016. Disabled women in Northern Ireland are experiencing an increasingly hostile environment.

#### Suggested questions

**What actions will the State take to address poverty and disadvantage experienced by disabled women?**

**What actions will the State take to end the abuse and exploitation of disabled women?**

#### List of Issues

1. What action will the Westminster Government take as co-guarantors of the Good Friday Agreement to ensure that the political institutions are re-established on a sustainable footing to ensure that there are mechanisms in place to advance legislation in Northern Ireland?
2. What actions will the State take to ensure that the state in Northern Ireland has access to appropriate resources to deliver public services?
3. What actions will the State take to ensure that the rights of disabled people are protected?
4. What measures will the State in Northern Ireland take to ensure that the UNCRPD is incorporated into law?
5. the UNCRPD is incorporated into law?
6. What actions will the state take to ensure a Bill of Rights is enacted in Northern Ireland?

- 7.** What action will the State in NI take to advance the reform of Adult Social Care ensuring that the right to independent living is protected in legislation and that funding is made available to advance improvements co-designed with disabled people?
- 8.** What actions will the State take to reopen the Independent Living Fund?
- 9.** What actions will the State take to ensure that Mental Health and Capacity Legislation is UNCRPD compliant? What actions will be taken by the State in Northern Ireland to ensure that adult safeguarding legislation is developed in partnership with disabled people and disabled people's organisations to ensure that all interventions are based on informed consent?
- 10.** What measures will be taken by the State in Northern Ireland to ensure that disabled people have access to justice in cases of alleged abuse?
- 11.** What actions will the State take to ensure that the current political crisis does not adversely impact on disabled people through the reduction in the building of accessible social homes, reductions in housing support and housing adaptations?
- 12.** What action will the State take to ensure that there is investment in transport options for disabled people?
- 13.** What actions will the State Party take in NI to ensure mandatory pay gap reporting and the introduction of action plans to address the disability pay gap?
- 14.** What actions will the State take to address the Disability Employment Gap in Northern Ireland?
- 15.** What steps are being taken to address challenges in access to employment by disabled people and that action is taken to introduce stronger equality

legislation to ensure that citizens in NI have the same protections as their counterparts in the UK and Ireland.

- 16.** What actions will the State take to ensure that disabled people have access to emergency relief payments on an equal basis with others?
- 17.** What actions will the State take to address the underlying causes of poverty?
- 18.** What steps will the State take to ensure that disabled people are afforded an adequate standard of living through the social security system?
- 19.** What actions will the State take to challenge negative stereotypes of disabled people?
- 20.** What actions will the State take to ensure that there is an enforceable legal framework through which to address disability hate crime?
- 21.** What action will the State take to ensure the full incorporation of the UNCRPD which includes a strategy for implementation and monitoring?
- 22.** How will the State develop indicators that will relate to the UNCRPD and be comparable against other devolved nations and internationally (and be inclusive of d/Deaf and disabled children and adults with disabilities)?
- 23.** What actions will the state take to ensure that Brexit does not undermine the rights of disabled people?
- 24.** What specific measures are being taken by the State to ensure that any requirements to ensure the full protection of the right to life for all people with d/Deaf and disabled people are being addressed?

- 25.** What actions will the state take to ensure that disabled people are fully involved in emergency planning?
- 26.** What actions will the State take to address poverty and disadvantage experienced by disabled women?
- 27.** What actions will the State take to end the abuse and exploitation of disabled women?

# Annex E:

## Shadow Welsh Report

### Disability Wales

Disability Wales is the national organization of disabled people's organizations in Wales. We focus on the promotion and use of the social model of disability and independent living throughout Wales.<sup>577</sup> Disability Wales contributed to the 2017 review and published a full report on the implementation of the United Nations Convention on the Rights of Disabled People in Wales in 2022.

### Introduction

This report illustrates that although some progress within the policy realm has been made, recent events such as the cost-of-living crisis and a continued problem with policy implementation by the Welsh Government,<sup>578</sup> mean that Wales is still not fully meeting their obligations under several issues within these articles. This report starts by setting out for the committee the context of devolution specifically in Wales, following which lists each relevant article in turn and the changes, both positive and negative, within Wales since the last review. We do have a particular concern regarding the incorporation of the United Nations Convention on the Rights of Disabled People into Welsh law. The last Senedd election saw cross-party consensus on incorporation, and it was committed to in both the initial Programme for Government published by the

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<sup>577</sup> Disability Wales, "About", < <https://www.disabilitywales.org/about/>>

<sup>578</sup> 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", <https://onlinelibrary.wiley.com/doi/abs/10.1111/jols.12273>

Welsh Government<sup>579</sup> and part of the cooperation agreement with Plaid Cymru,<sup>580</sup> a centre-left Welsh Nationalist party<sup>581</sup> which is the third largest party in the Senedd<sup>582</sup> and was previously in coalition with Welsh Labour in the One Wales Government from 2007-2011.<sup>583</sup><sup>584</sup> We are now seeming to run out of time for the introduction of this legislation within the current Senedd term, with no indication of a timeframe for incorporation.

We have found that Wales is a country which aspires to be a leader on equality, human rights and social justice, but there is limited implementation of policies. Our questions focus primarily on the implementation of Welsh Government policy, the poor quality of housing stock in Wales and how the Welsh Government uses the unique Welsh powers provided as a tactic to reduce poverty and to improve social security in Wales.

## Methodology

The findings of this report are based on a review of previously existing research done by Disability Wales, alongside contributions from Learning Disability

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<sup>579</sup> Welsh Government, 15<sup>th</sup> June 2021, “Programme for Government – Update”, <https://www.gov.wales/sites/default/files/publications/2022-01/programme-for-government-update-december-2021.pdf>

<sup>580</sup> “The Co-Operation Agreement 2021”, Welsh Government, 1st December (2021), p3, <https://www.gov.wales/sites/default/files/publications/2021-11/cooperation-agreement-2021.pdf>

<sup>581</sup> Plaid Cymru, website, <https://www.partyof.wales/>

<sup>582</sup> BBC Wales Politics, 8<sup>th</sup> May 2021, “Welsh election results 2021: Labour's road to victory in numbers”, <https://www.bbc.co.uk/news/uk-wales-politics-57026094>

<sup>583</sup> Rhodri Morgan and Ieuan Wyn Jones, 27<sup>th</sup> June 2007, “One Wales A progressive agenda for the government of Wales”, [http://news.bbc.co.uk/1/shared/bsp/hi/pdfs/27\\_06\\_07\\_owales.pdf](http://news.bbc.co.uk/1/shared/bsp/hi/pdfs/27_06_07_owales.pdf)

<sup>584</sup> Politics.co.uk, “Plaid Cymru”, <https://www.politics.co.uk/reference/plaid-cymru/>

Wales<sup>585</sup> and Fair Treatment for the Women of Wales.<sup>586</sup> Primarily, the Review into the Implementation of the United Nations Convention on the Rights of Disabled People in Wales from 2022 and “Barely Surviving: the impact of the cost-of-living crisis on disabled people in Wales” from 2023. We thank Learning Disability Wales and Fair Treatment for Women in Wales for their written contributions and all other interested groups who we discussed this evidence with.

We used data from three self-selecting surveys of disabled people, although totalling 158 individual responses, it is very likely that some of these will be the same individual responding to each survey. Data from focus groups held in 2020, 2021, 2022, and 2023 have also been used.

## Devolved Context

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

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<sup>585</sup> “Learning Disability Wales is a national charity representing the learning disability sector in Wales. We want Wales to be the best country in the world for people with a learning disability to live, learn and work.

We work with people with a learning disability and their families, Welsh government, local authorities, disabled people’s organisations and the voluntary sector so we can create a better Wales for all people with a learning disability.”, Learning Disability Wales, “About Us”, <https://www.ldw.org.uk/about-us/>

<sup>586</sup> “We support, inform, educate, and empower girls, women and those assigned female at birth (AFAB) in Wales who are suffering a range of health conditions and who are not receiving adequate (or fair) treatment. As ‘experts by experience’, we and our growing team of volunteers, advocate for women’s healthcare needs locally, nationally, and at a UK-level.”, Fair Treatment for the Women of Wales, “About Us”, <https://www.ftww.org.uk/about-us/>

restrictions, are assumed to be within the competency of the Welsh Government (WG).<sup>587 588 589</sup>

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 implementing the Social Model of Disability and the UNCRDP in Wales-specific human rights legislation, such as Action on Disability: The Right to Independent Living.<sup>590</sup> 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 representatives it is the only report of its kind in the UK<sup>591</sup> 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. One of the objectives of the Taskforce will be to revise policy to take account of disabled people's

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<sup>587</sup> Senedd Cymru, Welsh Parliament, How we work, History of Devolution 2021

<https://senedd.wales/how-we-work/history-of-devolution/>

<sup>588</sup> Welsh Parliament, (September 2020), "Powers", <https://senedd.wales/how-we-work/our-role/powers/?fbclid=IwAR0xQKfzsadohoJMa4oALuQby7tFQaQL31v-N3kmn5EmyvU6Pd2RkjtKxo8>

<sup>589</sup> House of Commons, (February 2016), "2 Moving to a Reserved Powers Model", <https://publications.parliament.uk/pa/cm201516/cmselect/cmwelaf/449/44904.htm>

<sup>590</sup> Welsh Government, (2019), Action on Disability: The Right to Independent Living , Policy Framework <https://gov.wales/sites/default/files/publications/2019-09/action-on-disability-the-right-to-independent-living-framework-and-action-plan.pdf>

<sup>591</sup> This inquiry resulted in the Locked Out report, which heavily criticised the Welsh Government's approach to the pandemic.

experiences during the pandemic. The governing Welsh Labour administration is also committed to enshrining the UNCRPD into Welsh law.<sup>592</sup>

## **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."

## **Independent Living – Article 19**

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

### **Article 19.1.a**

**Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;**

This right is not being enjoyed by all disabled people in Wales. Due to a lack of appropriate accommodation locally, some disabled people have reported having to move far from support networks or feeling forced into certain living situations due to the availability of accommodation. One disabled person reported that

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<sup>592</sup> Welsh Government, 15<sup>th</sup> June 2021, "Programme for Government – Update", <https://www.gov.wales/sites/default/files/publications/2022-01/programme-for-government-update-december-2021.pdf>

they experienced an attempt to force them to move into residential accommodation 50 miles away from their friends, they were told that a court order would be made to force them to accept accommodation. “[I] 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.”<sup>593</sup> This is not the only story of being forced into certain accommodation or a certain area, due to accommodation needs, we are concerned about the number of disabled people whose Article 19 rights are not being met.

Some support accommodation is also not available for some disabled applicants due to age limits. Some shelter housing only accepts applicants aged 55+, regardless of need.<sup>594 595 596</sup> One disabled person who we spoke to in a focus group in 2021 told us that they were only able to get access to the accommodation that they required because their non-disabled husband fit the age requirement. Should they have applied on their own, they would not have been able to gain access to the supported accommodation they require.<sup>597</sup> We believe that the continuation of this policy falls into stereotypes about both disabled and older people, not all disabled people are elderly and not all elderly people are disabled.

In information submitted to Disability Wales, Learning Disability Wales was concerned that significant numbers of people with a learning disability are

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<sup>593</sup> Respondent to 2023 Disability Wales survey

<sup>594</sup> Newport City Council, “Older people’s housing”, <https://www.newport.gov.uk/en/Planning-Housing/Housing/Older-peoples-housing/Older-peoples-housing.aspx>

<sup>595</sup> ClywdAlan, “Over 55 Housing”, <https://www.clwydalyn.co.uk/over-55-accommodation/>

<sup>596</sup> North Wales Housing, “For aged over 55”, <https://www.nwha.org.uk/find-a-home/our-homes/for-aged-over-55/>

<sup>597</sup> Participant in 2021 Disability Wales focus group on housing

denied the right to live where and how they want. They are too often disproportionately subjected to having their liberties restricted.<sup>598</sup>

They have heard from parents and carers that some people with a learning disability are being placed in secure mental health units because there is no adequate support available for them to live within the community.<sup>599</sup> Whilst the use of restrictive practices on people with a learning disability is concerning in general, we are additionally concerned about the disproportionate number of Black people being restrained in mental health settings.<sup>600 601</sup>

It is important to note that the mistreatment of people with a learning disability in secure units was not just a problem caused during the COVID-19 lockdowns, this issue continues to affect people with a learning disability in Wales.<sup>602</sup>

## **Article 19.1.b**

**Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to**

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<sup>598</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023, "Evidence from Learning Disability Wales on Articles of the UNCPR ", written submission.

<sup>599</sup> Dawn Cavanagh, August 2022, "‘Make them stop, Mummy’: A family’s experience of restrictive practice",

FPID Bulletin: The Bulletin of the Faculty for People with Intellectual Disabilities, <https://explore.bps.org.uk/content/bpsfpid/20/2>

<sup>600</sup> Emily Townsend, (2021), "‘Staggering’ rise in restraint of black people in mental healthcare", <https://www.hsj.co.uk/mental-health/staggering-rise-in-restraint-of-black-people-in-mental-healthcare/7033754.article>

<sup>601</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023, "Evidence from Learning Disability Wales on Articles of the UNCPR ", written submission.

<sup>602</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023, "Evidence from Learning Disability Wales on Articles of the UNCPR ", written submission.

## **support living and inclusion in the community, and to prevent isolation or segregation from the community;**

In response to our 2023 survey on the cost-of-living crisis, disabled people told us that they had to give up aspects of their in-home, residential, or other community support, for financial reasons. The measures taken include having to dismiss support workers, avoid using electrical equipment due to energy costs and not making necessary adaptations to their homes due to the cost.<sup>603</sup> <sup>604</sup> We are particularly concerned about the impact of the extra cost of disability, the issue that many disabled people have additional essential costs so therefore their money does not go as far.<sup>605</sup> “[There is] not enough funding for housing and support services. My home is not sufficiently accessible, but I have to make do and I have to pay too much of my income towards social care”, “I used to use my PIP on complementary therapies now it goes on living.”<sup>606</sup> This was a common story for us, this disabled person has many additional expenses that a non-disabled person may not have, but limited support for managing those expenses.

In Disability Wales’ 2023 survey on the cost-of-living crisis, disabled people reported feeling increasingly lonely and isolated, in a large part due to a lack of low-cost methods to socialise and see loved ones, “I cannot socialise or see family as I cannot afford the transport costs and this is also true for family members who provide unpaid care so visits are limited.” Of 74 participants, 58 disabled people had to cut back on leisure expenses and 53 people had to cut back on transport expenses.<sup>607</sup> The Welsh Government released a Loneliness and

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<sup>603</sup> Respondent to 2022 Disability Wales survey

<sup>604</sup> Respondent to 2023 Disability Wales survey

<sup>605</sup> Scope, (2023), “Disability Price Tag 2023: the extra cost of disability”, <https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag-2023/#What-needs-to-change>

<sup>606</sup> Two respondents to 2023 Disability Wales survey

<sup>607</sup> Respondent to 2023 Disability Wales survey

Social Isolation Strategy in 2020,<sup>608</sup> disabled people were highlighted as a target group, and the Welsh Government released a Loneliness and Social Isolation Fund which is running from 2021-2024,<sup>609</sup> currently, there is no information on its success.

We are pleased that the Disability Rights Taskforce has set up a working group on Independent Living (Social Care), this working group will look to develop recommendations on the right to independent living.<sup>610</sup>

### **Article 19.1.c**

**Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.**

Inaccessible transport infrastructure is a major barrier in Wales. Disability Wales research consistently shows us that a lack of access to public transport links is a key factor in the ability of disabled people to access key services in their area,

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<sup>608</sup> Welsh Government, 21<sup>st</sup> June 2022, "Connected Communities: A strategy for tackling loneliness and social isolation and building stronger social connections", <https://www.gov.wales/sites/default/files/publications/2020-02/connected-communities-strategy-document.pdf>

<sup>609</sup> Welsh Government, 21<sup>st</sup> June 2022, "Loneliness and social isolation fund 2021 to 2024", <https://www.gov.wales/loneliness-and-social-isolation-fund-2021-2024>

<sup>610</sup> Jane Hutt MS, Welsh Government, 29<sup>th</sup> March 2023, "Written Statement: Update on the Disability Rights Taskforce", <https://www.gov.wales/written-statement-update-disability-rights-taskforce>

<sup>611</sup><sup>612</sup> it was reported that in areas which had lost previously existing bus routes, or who had limited access to public transport had struggled to access in-person services in urban centres. The cost-of-living crisis has exacerbated this, our research from 2022/2023 shows that there is now the additional factor of the cost of public transport. Of the 74 respondents, 53 had to cut back on transport costs, as disabled people have had to cut back on their transport costs, many now have even more limited access than before, “Missed hospital apps and don't go for medical help when I'll as can't afford to (too young for a bus pass and can't afford to drive anymore).” <sup>613</sup> This example is one of many reports that disabled people were not able to access key support services, such as warm banks, or appointments, due to not being able to afford the transportation to get there.

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Rising fuel costs have been a key contributor to this, National Energy Action estimated that there were 900,000 disabled people living in fuel poverty in 2019, by 2023 this figure has severely increased to 2.1 million disabled people. <sup>617</sup> In response to our surveys in 2023, 2022, and 2021, the lack of affordability of fuel

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<sup>611</sup> Megan Thomas, Disability Wales, March 31st 2022, “Civil Society Shadow Report on the Implementation of the United Nations Convention on the Rights of Disabled People (UNCRDP) in Wales”, [https://www.disabilitywales.org/wp-content/uploads/2022/03/0637-PS\\_DW-Report.pdf](https://www.disabilitywales.org/wp-content/uploads/2022/03/0637-PS_DW-Report.pdf)

<sup>612</sup> Megan Thomas, Disability Wales, 10th July 2023, “Barely Surviving: The Impact of the Cost-of-Living Crisis on Disabled People in Wales”, <https://www.disabilitywales.org/wp-content/uploads/2023/07/Barely-Surviving-The-Impact-of-the-Cost-of-Living-Crisis-on-Disabled-People-in-Wales.pdf>

<sup>613</sup> Respondent to 2023 Disability Wales survey

<sup>614</sup> Respondent to 2022 Disability Wales survey

<sup>615</sup> Respondent to 2023 Disability Wales survey

<sup>616</sup> Participants in 2023 Disability Wales focus group

<sup>617</sup> Scope, “Charities warn number of disabled households in fuel poverty set to double by end of year”, 17<sup>th</sup> March (2022), <https://www.scope.org.uk/media/press-releases/fuel-poverty-set-to-double/>

for cars was a significant barrier to many disabled people from accessing their form of transportation. Many disabled people use private vehicles for specific reasons, some are unable to use some forms of public transport due to their impairments, for example, one person we spoke to in 2021 did not use buses as the vibrations could trigger their impairment.<sup>618</sup> Some use private vehicles out of necessity due to the inadequate provision of public transport in Wales.<sup>619 620 621</sup>

Poor quality services have led to disabled people in Wales not being able to access other support services. A key example is warm banks during the cost-of-living crisis, the Welsh Government invested £1 million into warm banks,<sup>622</sup> few disabled people who responded to our survey used this service, of those who considered using the service but did not, many said it was because they were not able to travel there “I'm housebound, plus the nearest one to me is a 40 mile round trip which would cost a lot in fuel for the car.” Having to travel during cold weather and the continued risk of COVID-19 were also identified as barriers “Anything that involves movement or where I may catch COVID is no go activity for me.” This is a common sentiment that was applied to many other community services that would otherwise be available.<sup>623 624</sup>

A key policy for this article is “Framework for Action on Disability: The Right to Independent Living”, which is Welsh Government’s action plan aimed at reducing or removing social barriers to equality experienced by disabled people. The Framework identified these areas of concern “advice and information, advocacy; personal care and support; person centred technology; employment;

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<sup>618</sup> Participant in 2021 Disability Wales focus group

<sup>619</sup> Respondent to Disability Wales survey 2022

<sup>620</sup> Respondent to Disability Wales survey 2023

<sup>621</sup> Participant in Disability Wales focus group 2023

<sup>622</sup> David Deans, BBC Wales News, 20<sup>th</sup> September 2022, “Warm banks to get cash from Welsh government”, <https://www.bbc.co.uk/news/uk-wales-politics-62968256>

<sup>623</sup> Respondent to 2023 Disability Wales survey

<sup>624</sup> Participant in 2023 Disabled People’s Organisations Network meeting

housing; transport; and access to places.”<sup>625</sup> The plan was developed in consultation with disabled people, but there is currently no published review of its impact.

The Welsh Government launched the £144 million Health and Social Care Regional Integration Fund, which will run from 2022-2027. The fund seeks to create change using health and social care integration, over the five-year period they aim to have established six new national models of integrated healthcare.<sup>626</sup> As the fund is recently established and ongoing there is currently no data on its progress. Disability Wales has welcomed the Welsh Government’s commitment to a National Care Service;<sup>627</sup> however, we do not have information of how it will operate.

There is a concern about the lack of funding allocated to disabled people’s organisations that provide essential support. In a network roundtable, representatives of disabled people’s organisations told us that they have found it difficult to provide the vital services that they deliver due to a lack of resources.<sup>628</sup> One well-published example is Aubergine Café, a Cardiff-based café and community arts organisation set up by and entirely staffed by autistic people.

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<sup>625</sup> Welsh Government, (2019), Action on Disability: The Right to Independent Living , Policy Framework <https://gov.wales/sites/default/files/publications/2019-09/action-on-disability-the-right-to-independent-living-framework-and-action-plan.pdf>

<sup>626</sup> Welsh Government, “Health and Social Care Regional Integration Fund Revenue Guidance 2022-2027”, 22<sup>nd</sup> February 2022, <https://www.gov.wales/sites/default/files/publications/2022-02/health-and-social-care-regional-integration-fund-revenue-guidance-2022-2027.pdf>

<sup>627</sup> Welsh Government, “Establishing a National Care and Support Service for Wales”, 10<sup>th</sup> November 2022, <https://www.gov.wales/establishing-national-care-and-support-service>

<sup>628</sup> Participant in 2023 Disabled People’s Organisations Network meeting

The Café does significant work within the autistic community in Cardiff but lost their physical space due to rising rent costs.<sup>629</sup>

People with a learning disability often do not receive the support they need to participate fully in society. One way that this expresses itself is through a reduction in day service hours people with a learning disability receive. A recent survey of people with a learning disability conducted by Mencap Cymru found that most of the respondents had experienced a significant reduction of support hours compared to before the begin of the pandemic. 73% of the people in the study experienced an overall cut of services they received.<sup>630 631</sup>

The support that people with a learning disability receive is often only available during the day. This in turn means that people with a learning disability are denied the support they need to participate in evening activities and to develop their social skills, relationships and civic engagements. To be able to fully participate and be included in society it is important that support is improved for people to take part in social activities, at any time of day.<sup>632</sup>

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<sup>629</sup> Sanjana Idnani, BBC Wales News, 23<sup>rd</sup> December 2022, "Cardiff Cafe staffed by autistic people fears closure", <https://www.bbc.co.uk/news/uk-wales-63911682>

<sup>630</sup> Mencap Cymru: The Future of Day Services, available online at: [https://wales.mencap.org.uk/sites/default/files/2023-07/Future%20of%20Day%20Services%20Mencap%20Cymru.pdf?fbclid=IwAR1zGKu1US4H6q4S4Vd0xmvHKyB1v-aMLljd6wchjt09w8YI\\_DatjYQujl](https://wales.mencap.org.uk/sites/default/files/2023-07/Future%20of%20Day%20Services%20Mencap%20Cymru.pdf?fbclid=IwAR1zGKu1US4H6q4S4Vd0xmvHKyB1v-aMLljd6wchjt09w8YI_DatjYQujl)

<sup>631</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023, "Evidence from Learning Disability Wales on Articles of the UNCPR ", written submission.

<sup>632</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023, "Evidence from Learning Disability Wales on Articles of the UNCPR ", written submission.

## Article 27– Work and Employment

### Article 27.1

**States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:**

The Welsh Government does not have competency over employment law or the welfare system but does have the ability to create and support alternative schemes and resources to support people into work, or support employers. One key example is through the Employment and Skills Plan,<sup>633</sup> The Welsh Government has created the role of “Disabled People’s Employment Champion”, which seeks to work within a network of partners to improve employment opportunities for disabled people, 5 disabled people were appointed as champions and the Welsh Government has recently recruited an additional 6.<sup>634</sup>  
<sup>635</sup> It is too early to assess the impact of this role, but we are pleased at the

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<sup>633</sup> Welsh Government, 8<sup>th</sup> March 2022, “Stronger, fairer, greener Wales: a plan for employability and skills”, <https://www.gov.wales/stronger-fairer-greener-wales-plan-employability-and-skills-summary-html>

<sup>634</sup> Welsh Government, 2023, “Vacancy - Disabled People’s Employment Champion x4”, job advert, <https://cymru-wales.tal.net/vx/lang-en-GB/mobile-0/appcentre-1/brand-2/candidate/so/pm/1/pl/6/opp/8570-Disabled-People-s-Employment-Champion-x4/en-GB>

<sup>635</sup> McNally, 26<sup>th</sup> March 2021, “Network of Disabled People’s Employment Champions Announced”, Business News Wales, <https://businessnewswales.com/network-of-disabled-peoples-employment-champions-announced/>

action. The Disability Rights Taskforce has also created a specific working group to explore the topic of disabled people and employment.<sup>636</sup>

The Welsh Government has committed to expanding their “Communities for Work” programme, which since 2015 has supported 41,000 “individuals with complex barriers.” They have pledged to double the original £12 million budget; the Employment and Skills Plan confirms disabled people continue to be a key group targeted by programs such as Communities for Work.<sup>637</sup>

### **Article 27.1.d**

**Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;**

A key policy on this is the Disability Action Plan for Apprenticeships, which set out a three-year plan for supporting disabled people to take up apprenticeships as a way of providing training and support to enter the workforce. Since its publication in 2018, we have not seen any follow up information on the success of the scheme published.

Learning Disability Wales notes that the Welsh Government has been working to improve access to supported employment. The policy A Stronger, Greener, Fairer Wales WG Employability and Skills Plan includes specific endorsements of

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<sup>636</sup> Jane Hutt MS, Welsh Government, 29<sup>th</sup> March 2023, “Written Statement: Update on the Disability Rights Taskforce”, <https://www.gov.wales/written-statement-update-disability-rights-taskforce>

<sup>637</sup> Welsh Government, “Stronger, fairer, greener Wales: a plan for employability and skills”, 8<sup>th</sup> March 2022, <https://www.gov.wales/stronger-fairer-greener-wales-plan-employability-and-skills-summary-html>

job coaching and supported employment,<sup>638</sup> and the Learning Disability Delivery and Implementation Plan 2022 to 2026 endorses more measures based on supported employment.<sup>639</sup> The Young Person’s Guarantee pledges that all young people will be supported to access education, training and employment.<sup>640</sup> It is a concern that plans, and availability of supported employment vary across Wales, meaning that not everyone in Wales has equal access. Funding for parts of this support come from the Department of Work and Pensions (DWP) via Access to Work.<sup>641</sup> There continues to be a significant backlog in claiming this funding resulting in delays to provision of support. A WG grant available for individuals to overcome barriers to employment is far from sufficient to enable adequate job coach support. For some disabled people going off benefits to enter work can be risky, as they may be put on lower benefits if they must return to them, should their employment have ended.<sup>642</sup>

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<sup>638</sup> Welsh Government, 8<sup>th</sup> March 2022, “Stronger, fairer, greener Wales: a plan for employability and skills”, <https://www.gov.wales/stronger-fairer-greener-wales-plan-employability-and-skills-summary-html>

<sup>639</sup> Welsh Government, 27<sup>th</sup> March 2023, “Learning disability delivery and implementation plan 2022 to 2026”, <https://www.gov.wales/sites/default/files/publications/2022-10/learning-disability-delivery-and-implementation-plan.pdf>

<sup>640</sup> Welsh Government, 27<sup>th</sup> March 2023, “<https://www.gov.wales/young-persons-guarantee-html>”, <https://www.gov.wales/young-persons-guarantee-html>

<sup>641</sup> Welsh Government, 27<sup>th</sup> March 2023, “Learning disability delivery and implementation plan 2022 to 2026”, <https://www.gov.wales/sites/default/files/publications/2022-10/learning-disability-delivery-and-implementation-plan.pdf>

<sup>642</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023, “Evidence from Learning Disability Wales on Articles of the UNCPR”, written submission.

## **Article 27.1.g**

### **Employ persons with disabilities in the public sector.**

In December 2020, 6% of employees in the Welsh public sector were disabled. According to their Workplace Equality, Diversity and Inclusion Strategy (2021-2026), they aim to raise this to 20% of their workforce identifying as disabled people pledging to use positive action methods to achieve this goal.<sup>643</sup> There is a lack of up-to-date data on the number of disabled people who have been hired after two years of the strategy.

## **Article 27.1.h**

Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;

The Welsh Government funded a course on Business Wales, aimed at educating employers on having disabled employees. This module aims to break down barriers and perceptions of disabled employees to help businesses feel more confident to employ disabled people. The course was developed by Disability Wales, in close collaboration with disabled people affected.<sup>644</sup>

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<sup>643</sup> Welsh Government, 10<sup>th</sup> June 2021, "Workforce equality, diversity and inclusion strategy: 2021 to 2026", <https://www.gov.wales/workforce-equality-diversity-and-inclusion-strategy-2021-to-2026-html>

<sup>644</sup> Business Wales, "Supporting Disabled Employees", <https://businesswales.gov.wales/responsible-business/supporting-disabled-employees>

## Article 28 – Adequate Standard of Living and Social Protection

### Article 28.1

**States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.**

Disability Wales surveys on the cost-of-living crisis both in 2022 and 2023 painted a stark picture of the standard of living for some disabled people in Wales. Many disabled people reported not having access to enough food, some only eating one or two meals a day. “I have changed to cheaper food choices but it is hard when you have additional dietary needs and you have food allergies. I am cutting out meals. I eat just breakfast now. I don’t know what else I can cut out!”<sup>645</sup> Food can be more expensive for some disabled people who have specific dietary requirements or who eat pre-pared or prepped food due to access requirements.<sup>646</sup>

We are concerned about significant regression in living conditions for some disabled people. Many reported no longer being able to afford to heat their homes or to maintain their homes in a safe condition.<sup>647 648 649</sup> In a 2022 report to the committee, the Welsh Government reported support for care and repair

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<sup>645</sup> Respondent to 2023 Disability Wales survey

<sup>646</sup> Scope, November 2022, “Do the Right Thing: Supporting disabled people through the cost-of-living crisis”, <https://www.scope.org.uk/campaigns/research-policy/cost-of-living-report/>

<sup>647</sup> Respondents to 2022 Disability Wales survey

<sup>648</sup> Respondents to 2023 Disability Wales survey

<sup>649</sup> Participants in 2023 Disability Wales focus groups

schemes for homes,<sup>650</sup> but these schemes are still limited and we still hear reports of disabled people who are living in unsuitable housing due to not being able to afford to make changes, “I own my own property and house maintenance is a major problem, costs of trades has risen not to mention materials and no help with these costs at all.” We are concerned that disabled people are being left in unsuitable accommodation due to a lack of funds.

Learning Disability Wales has shared concerns that parents with a learning disability are not receiving the support they need while also being subjected to higher scrutiny than other parents. The lack of support, potentially living in poverty and stigma could result in children of parents with a learning disability more likely to be taken into care than other children. The Welsh Government recently published guidance for social workers working with parents with a learning disability.<sup>651</sup> This will go some way towards improving the situation. But in order to enable families where a parent has a learning disability to live good lives and take care of their children, parents will need better material support in terms of being able to provide a good standard of living for their children.<sup>652</sup>

## **Article 28.2**

States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of

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<sup>650</sup> Committee on the Rights of Persons with Disabilities, United Nations Convention on the Rights of Persons with Disabilities, 30<sup>th</sup> September 2022, “Inquiry concerning the United Kingdom of Great Britain and Northern Ireland conducted under article 6 of the Optional Protocol to the Convention: Follow-up report submitted by the United Kingdom of Great Britain and Northern Ireland”, Addendum.

<sup>651</sup> Guidance for social workers for families where the parent has a learning disability , available online here: <https://www.gov.wales/guidance-social-workers-families-where-parent-has-learning-disability-html>

<sup>652</sup> Grace Krause, Learning Disability Wales, received on 31st July 2023,” Evidence from Learning Disability Wales on Articles of the UNCPR “, written submission.

disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

Poverty is an overwhelming barrier, one survey respondent described poverty as a “fact for disabled people in Wales”.<sup>653</sup> Welfare is mostly reserved, but the Welsh Government has competency over some benefits which are distributed by local authorities, such as direct payments<sup>654</sup> and local housing allowance (LHA).<sup>655</sup> Our 2022 and 2023 surveys on the cost-of-living crisis revealed low levels of knowledge of the support services that had been made available. Welsh social security benefits such as Winter Fuel Allowance or Discretionary Assistance Fund had relatively low levels of awareness, this was particularly poor for Discretionary Assistance Fund with in 2023 only 30 of the 74 respondents to the survey having prior knowledge of the fund. Disability Wales has been calling for more active promotion of the support available by the Welsh Government and local authorities, particularly of Discretionary Assistance Fund and Local Housing Allowance.

The Socio-economic Duty, established in 2020, requires all public bodies in Wales to consider the impact on those with socio-economic disadvantage in all their activities.<sup>656</sup> Local authorities in Wales reported encouraging short-term

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<sup>653</sup> “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.

<sup>654</sup> Citizens Advice, “Using Direct Payments for Care”, <https://www.citizensadvice.org.uk/wales/family/looking-after-people/direct-payments-w/using-direct-payments-for-care-w/>

<sup>655</sup> Welsh Government, (March 2019), “Local Housing Allowance”, <https://gov.wales/local-housing-allowance>

<sup>656</sup> Welsh Government, “Socio-economic duty: an overview”, 14th September 2020, <https://www.gov.wales/socio-economic-duty-overview>

results from the Duty and have identified supporting those with some protected characteristics, namely disabled people and racialised people as key targets.<sup>657</sup>

The Social Services and Wellbeing (Wales) Act (2014) was referred to by disabled people responding to a Disability Wales survey as not fully delivering on what was promised. The Act was designed alongside disabled people and disabled people's organisations and imposes duties on local authorities, health boards, and Welsh Ministers to promote the well-being of disabled people and carers.<sup>658</sup> The Act has been in action since 2016, but 6 years on and according to disabled people we spoke to, many of the stated issues remain.<sup>659</sup>

Immigration policy and support for those without recourse to public funds has resulted in those who have leave to remain without recourse to public funds being unable to enjoy these rights. This means that disabled people who are not entitled to these social security benefits do not have the same level of social protection as disabled people who are naturalised citizens or were born in the UK.<sup>660</sup> The Welsh Government has published guidance on how to use the Social Services and Wellbeing Act (Wales) (2014) in these circumstances,<sup>661</sup> but there is

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<sup>657</sup> Elaine Wilson Smith, Diego Garcia Rodriguez and June Brawner, Equality and Human Rights Commission, "Evaluating the socio-economic duty in Scotland and Wales", 2<sup>nd</sup> March 2021, <https://www.equalityhumanrights.com/sites/default/files/evaluating-the-socio-economic-duty-in-scotland-and-wales.docx>

<sup>658</sup> Welsh Government, (2014), Social Services and Wellbeing (Wales) Act 2014, [https://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw\\_20140004\\_en.pdf](https://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf)

<sup>659</sup> "The 2014 Act should have been a protective measure but most local authorities have ignored or resisted it" respondent to 2023 Disability Wales survey.

<sup>660</sup> NRPF Network, "Immigration status and entitlements: How immigration status affects eligibility for public funds and other services", <https://nrpfnetwork.org.uk/information-and-resources/rights-and-entitlements/immigration-status-and-entitlements/overview#guide-content>

<sup>661</sup> Welsh Government, (2014), Social Services and Wellbeing (Wales) Act 2014, [https://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw\\_20140004\\_en.pdf](https://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf)

a limited amount of information on its impact and the effect on disabled people without recourse to public funds.

### **Article 28.2.b**

To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

Disability Wales is concerned that the Welsh Government’s free school meals scheme is not extended over the summer holiday.<sup>662</sup> Research shows that households containing a disabled person are more likely to experience poverty, further research has shown that children with at least one disabled parent are more likely to live in poverty.<sup>663</sup> Child poverty is a significant issue in Wales, 34% of Welsh children are estimated to live in poverty<sup>664</sup> and access to food was repeatedly raised in our survey on the cost-of-living crisis.<sup>665 666</sup> We are concerned that this approach is not appropriate for the current financial circumstances and the possibility that some children in Wales will not have access to enough food during the holiday period.

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<sup>662</sup> Rhys Williams, 26<sup>th</sup> July 2023, “Morally unacceptable’: Welsh government slammed after cutting free school meals support”, <https://www.itv.com/news/2023-07-26/morally-unacceptable-welsh-government-cuts-free-school-meals-support>

<sup>663</sup> Joseph Roundtree Foundation, 20<sup>th</sup> January 2023, “UK Poverty 2023 – The essential guide to understanding poverty in the UK”, [https://www.irf.org.uk/sites/default/files/jrf/uk\\_poverty\\_2023\\_-\\_the\\_essential\\_guide\\_to\\_understanding\\_poverty\\_in\\_the\\_uk\\_0\\_0.pdf](https://www.irf.org.uk/sites/default/files/jrf/uk_poverty_2023_-_the_essential_guide_to_understanding_poverty_in_the_uk_0_0.pdf)

<sup>664</sup> Juliet Stone, Centre for Research in Social Policy Loughborough University, July 2022, “Local indicators of child poverty after housing costs, 2020/21”, [https://endchildpoverty.org.uk/wp-content/uploads/2022/07/Local-child-poverty-indicators-report-2022\\_FINAL.pdf](https://endchildpoverty.org.uk/wp-content/uploads/2022/07/Local-child-poverty-indicators-report-2022_FINAL.pdf)

<sup>665</sup> Respondent to 2022 Disability Wales survey

<sup>666</sup> Respondent to 2023 Disability Wales survey

### **Article 28.2.c**

To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

Our surveys on the cost-of-living crisis have shown that there are disabled people in Wales who have had to give up some of their care and various therapies due to the cost. Some disabled people reported that they could no longer afford these services due to having to use their Personal Independence Payments to cover household bills, instead of the services that were their primary purpose, “I used to use my PIP on complimentary therapies now it goes on living.” Disabled people have reported having to let go of cleaners, support workers and other care providers because they could no longer afford to employ them.” “Extra help and therapies have gone due to a lack of affordability.” Disabled people also reported to no longer be able to afford new equipment such as glasses and to maintain their current access equipment.<sup>667</sup>

There are schemes in Wales and in the UK, delivered by local authorities which can help cover the cost of equipment, care, and counselling services,<sup>668</sup> but in the absence of robust, long-term support for the ongoing cost-of-living crisis, these support services cannot be used for their intended purposes. This again is an issue that, whilst the lack of cost-of-living support is not directly disablist discrimination, it has the effect of disproportionately harming disabled people.

### **Article 28.2.d**

To ensure access by persons with disabilities to public housing programmes;

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<sup>667</sup> Respondent to 2023 Disability Wales survey

<sup>668</sup> Cardiff Council, “Disabled Facilities Grant”, <https://www.cardiff.gov.uk/ENG/resident/Social-Services-and-Wellbeing/Disability/disabled-facilities-grant/Pages/default.aspx>

There is a problem with the stock of social housing in Wales. Council homes are not being built quick enough to reach their stated goals and this does have an impact on where disabled people can live. 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,<sup>669</sup>  
<sup>670</sup> <sup>671</sup> 67% of respondents to a survey conducted by the Bevan Foundation supported building more social housing.<sup>672</sup> We are concerned about the impact of a lack of social housing on disabled people trying to access accommodation, particularly in their choice.

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<sup>669</sup> Simon Hoffman, Tai Pawb, (June 2019), The Chartered Institute of Housing Cymru and Shelter Cymru, The Right to Adequate Housing in Wales: Feasibility Report, <https://www.taipawb.org/wp-content/uploads/2019/06/RightToHousing-Full-ENG.pdf>

<sup>670</sup> Mike Hedges MS, Bevan Foundation, “Build Build Build”, (February 2022), <https://www.bevanfoundation.org/views/build-build-build/>

<sup>671</sup> Rob Simkins, Shelter Cymru, (December 2020), “Politicians Have Listened to Our Social Housing Campaign. Now its Time for them to Take Action”, <https://sheltercymru.org.uk/politicians-have-listened-to-our-social-housing-campaign-now-its-time-for-them-to-take-action/>

<sup>672</sup> Bevan Foundation, A Snapshot of Poverty in Winter 2021, (December 2021), <https://www.bevanfoundation.org/wp-content/uploads/2021/12/A-snapshot-of-poverty-in-winter-2021-.pdf>

