

Disability Strategy Expert Advisory Panel

Report & Recommendations

December 2020

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1.0 Introduction

1.1 Context

This report has been developed by the Disability Strategy Expert Advisory Panel appointed by the Department for Communities, comprised of Dr. Bronagh Byrne, Seán Fitzsimons, Tony O'Reilly and Professor Eilionóir Flynn. Members of the panel have experience of the d/Deaf and disabled people's movement and also academic expertise in international human rights law and in particular the UN Convention on the Rights of Persons with Disabilities (CRPD). In developing this report, the panel chose to focus on the General Principles of the CRPD set out in Article 3 of the Convention, as a guide to what should be included in any Disability Strategy. This is primarily because the General Principles in Article 3 of the CRPD effectively summarise all of the issues which are addressed in the Convention and which need to be implemented in domestic legislation and policy.

However, as with any report or piece of research, there are areas that require further development and elaboration. This report takes an illustrative rather than exhaustive approach to the themes and topics which can be addressed in the next Disability Strategy for Northern Ireland. With this in mind, the panel feel that there are four core priorities underpinning this present report which should be reflected in the final Disability Strategy:

- Participation and leadership of d/Deaf and disabled people (recognising their multiple identities and spanning the entire spectrum of disability)
- Economic security of d/Deaf and disabled people
- Autonomy of d/Deaf and disabled people
- Resources to achieve the Strategy's objectives

In this report, we primarily use the term ‘d/Deaf and disabled people’ when writing as the panel and the term ‘persons with disabilities’ when quoting directly from the CRPD. The term ‘disabled people’ is recognised by the disability rights movement in the UK to align with the social and human rights model of disability, as it is considered to acknowledge the fact that people with an impairment are disabled by barriers in the environment and society. However we recognise that others prefer the term “persons with disabilities” because of the inherent understanding in the term that they are first and foremost human beings entitled to human rights. Secondly it is the language used in the CRPD. The terminology used in the final Disability Strategy must be agreed with and acceptable to d/Deaf and disabled people in Northern Ireland.

The recommendations and measures proposed by the panel in this report are to be taken as a starting point and should provide guidance for further work and development, especially by the Disability Strategy Co-Design Group, and by d/Deaf and disabled people more broadly during an inclusive process of public consultation. Therefore, we anticipate that the Disability Strategy Co-Design Group will expand further on these recommendations and add and remove recommendations as they deem appropriate.

1.2 Terms of Reference

According to its Terms of Reference, the Panel was established to:

- help the Department for Communities to understand the experience of, and issues faced by, d/Deaf and disabled people for whom the Strategy will deliver, and advise the Department for Communities on appropriate methods of stakeholder engagement in the development of the Strategy

- analyse available evidence from the external research community and academia to present to the Department for Communities a baseline position to inform development of the Disability Strategy
- make evidence-based recommendations to the Minister for Communities on the scope of a new Disability Strategy, the time period it should cover, and the themes, content and key actions that should be included within it
- make recommendations on the gaps in provision across all NICS departments that should be addressed by a new Disability Strategy
- ensure that the recommended themes and actions for a new Disability Strategy are aligned to the Programme for Government and informed by the relevant international obligations
- present clear recommendations for the use of the Disability Strategy Co-Design Group and the Department for Communities in developing and drafting the Disability Strategy and Disability Strategy Action Plan. These recommendations will have been discussed and agreed with the Co-design Group prior to finalisation. The recommendations will be published following their presentation to the Minister for Communities
- advise the Department for Communities on the monitoring and reporting framework that should be established to ensure effective implementation of the Disability Strategy

While the Panel has an advisory role in setting direction for the development of the new Disability Strategy and making recommendations on its themes and content, final decisions on the content of the Disability Strategy and the actions associated with it will be the responsibility of the Department for Communities and the Minister for Communities, prior to the draft Disability Strategy being presented for public consultation and Executive agreement.

1.3 Method

The Panel has used a desk-based research method to compile this report as, due to severe time constraints, there was no time to go in-depth to examine qualitative and secondary data. In approaching the research, the panel was guided by the CRPD, and especially Article 3 on its General Principles. At the outset of its work, the Panel members considered various possible frameworks for the report based on ways of grouping together the rights and principles of the CRPD, and having considered various options, settled on a framework that combined the approach of Article 3 CRPD with General Comment 5 of the Committee on the Rights of the Child, which sets out general measures of implementation of human rights obligations by States.¹

For each specific topic addressed throughout the report, the panel considered different ways in which the topic could be structured. The main methods for addressing topics considered were: the four As (accessibility, affordability, availability and acceptability); and a more human rights-focused approach (issue, human rights obligations, barriers and recommendations/measures proposed). Having considered both options, the panel decided that the latter, human rights-focused approach worked better for a greater number of topics and was more in keeping with the general principles of CRPD which informed the entire report. Each panel member took initial responsibility to draft various sections of the report, and all panel members had the opportunity to comment on each of the sections developed by others. Given the time constraints, the panel focused our discussions as a group on agreeing the measures proposed under each of the issues covered in this report, and these measures have been collectively agreed and signed off on by the panel as a whole.

¹ United Nations Committee on the Rights of the Child (2003) General Comment No.5: General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6). UN, CRC/GC/2003/5

However, as noted previously, the measures included in this report are not set in stone and merely represent a starting point for further discussion in the Disability Strategy Co-design Group. The panel recognises that several of the measures proposed are very ambitious, and has, where possible, included recommendations on steps which can be taken in the short or medium term, since achieving some of the more ambitious measures proposed may take a much longer period of time to achieve.

1.4 Scope of the Strategy

The terms of reference, drafted by the Department for Communities and agreed to by all Panel members, was to advise the Department and the Disability Strategy Co-design Group on the priorities and themes upon which a cross-departmental Disability Strategy and supporting action plan should be developed. Therefore, the Panel's remit was to focus on d/Deaf and pan-disability issues relevant to Northern Ireland as a whole, and those substantive priorities and issues within the competence of the Northern Ireland Executive and the Assembly.

The recommendations of this report are solely directed at government departments. We sought to address our primary goal of ensuring that the task of developing a comprehensive Northern Ireland strategy delivering on d/Deaf and disabled people's human rights was primarily the responsibility of all in government working in partnership with d/Deaf and disabled people and their allies to make rights a reality.

Furthermore the scope of our recommendations does not address in any substantive way the very real concerns d/Deaf and disabled people have about the Brexit negotiations as a result of the EU Withdrawal Act 2018 or the potential reality that, despite the commitment in the Good Friday Belfast Agreement 1998 to ensure that there will be a non-diminution (loss) of our

existing rights, it is conceivable that those rights will no longer be further advanced through developments in equality law in Europe, which has strengthened our own disability equality and anti-discrimination legislation in the past. The loss of European funding of a wide range of disability projects in Northern Ireland, the potential adverse impacts on d/Deaf and disabled people related to, for example, cross-border travel, including the potential increased costs and additional red tape associated for people with assistance dogs, are major concerns.

We have however given some consideration in the report to the possible development of a new Bill of Rights and its significance for d/Deaf and disabled people living in Northern Ireland. Some reflection is given on the UK Government's commitment to date, regrettably, to repeal the Human Rights Act 1998 (which incorporates the European Convention on Human Rights in domestic law); however as with all our recommendations and observations this issue will require further examination from the Disability Strategy Co-design Group, the relevant government departments and the Northern Ireland Assembly.

This report should be read in light of the commitments set out in the January 2020 New Decade, New Approach document. It is also vital that the recommendations set out in this report are aligned with other existing Strategies or those being developed. This includes the other Social Inclusion Strategies, the Children and Young People's Strategy and the Disability Employment Strategy.

1.5 Definitions

This report uses the term 'd/Deaf and disabled people' to acknowledge and encapsulate the cultural and linguistic identity of the Deaf community,

building on the approach taken by civil society in the most recent shadow reporting process to the CRPD Committee.

The CRPD definition of disability underpins the content of the report. Under Article 1 of the CRPD: Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

As such, the measures set out in this report are intended to apply to people with a range of impairments, acknowledging the range of barriers that negatively impact on their full participation in our society. We are particularly mindful of the divergence in definitions of disability in law and policies in Northern Ireland, and hope that, in line with our recommendations on equality and non-discrimination in this report, that a more progressive and single definition that is compliant with the CRPD can be achieved.

1.6 Report Structure

The remainder of the report is structured as follows. Section 2 sets out the General Measures of implementation for the Disability Strategy. These are cross-cutting issues that affect the Strategy as a whole and will determine the level of its impact on the day to day lives of d/Deaf and disabled people in Northern Ireland. This section includes the need for the Strategy to give effect to the CRPD, the participation of d/Deaf and disabled people in the design, implementation and monitoring of the Strategy, leadership and governance of the Strategy, transparency and accountability, resources, data collection and indicators, awareness-raising and Strategy duration. The structure used in some of these sections varies slightly depending on the scope of the issue being discussed. Discrete issues, such as resources, include only the 'issue' and 'measures' sub-headings, while other

substantive issues, such as participation, follow the ‘issue, human rights obligations, barriers and measures’ structure which is replicated in all the remainder of the report, from section 3 onwards.

Sections 3-6 of the report address the following substantive issues respectively: autonomy and independent living, equality and non-discrimination, accessibility, and intersectionality. The decision to focus on these substantive areas is again driven by the General Principles of the CRPD in Article 3. Within autonomy and independent living, the panel has addressed legal capacity, independent living, social protection and adequate standard of living, welfare reform, deinstitutionalisation, right to liberty and freedom from violence. Section 4 on equality and non-discrimination is a stand-alone section focusing on legislative protections for d/Deaf and disabled people in Northern Ireland. Section 5 on accessibility includes transport, employment, education, health, justice, political and public life and emergency planning. Section 6 on intersectionality includes children and young people, gender equality, ethnic minority groups, LGBTQI+ community, asylum seekers, migrants and refugees, and older people. These are followed by an overall Conclusion in Section 7, summarising the key contributions of the report.

2.0 General Measures

This first section presents a set of cross-cutting themes and recommendations which should underpin the development, implementation and monitoring of a Disability Strategy for Northern Ireland. These factors can be understood as critical success factors or supportive architecture upon which the strategy should be based and include: giving effect to the CRPD; participation; leadership and governance; transparency and accountability; resources; data and indicators; awareness raising; and strategy duration.

2.1 Giving effect to the UNCRPD

Issue

Limited measures have been taken to give effect to the CRPD in Northern Ireland. Other jurisdictions in the UK are beginning to explore how the CRPD can be given direct and legal effect; for example, a legal scoping study has been commissioned in Scotland while in Wales this is being explored as part of research commissioned by the Welsh Government on options for Advancing and Strengthening Equality and Human Rights in Wales. There is already precedence across the UK for giving legal effect to human rights treaties in different ways. For example, the Scottish Government introduced a legislative bill on the incorporation of the UN Convention on the Rights of the Child (CRC) earlier this year. In NI, under the Children's Services Cooperation Act (NI) (2015) regard is to be had to any relevant provision of the CRC in determining the meaning of well-being for the purposes of this Act. In Wales, the Rights of Children and Young Persons (Wales) Measure (2011) requires Ministers to have due regard to the requirements of the CRC

and its Optional Protocols when making decisions about a provision to be included in an enactment, or the formulation of a new policy and/or legislation, or a review of or change to an existing policy and/or legislation. In Scotland, the Children and Young People Act (Scotland) (2014) places a duty on Scottish Ministers to keep under consideration whether there are any steps which they could take which would or might secure better or further effect in Scotland of the CRC requirements.

These discussions cannot be considered in isolation from a Northern Ireland Bill of Rights and the Ad Hoc Committee on a Bill of Rights public consultation which is taking place at the time of writing on whether there should be a Bill of Rights here and which rights such a Bill would include.

Human Rights Obligations

Article 4 of the CRPD requires States Parties to adopt all appropriate legislative, administrative and other measures for the implementation of the rights in the Convention. The CRPD Committee has called on the UK to incorporate the Convention into its legislation, including all devolved governments.

Barriers

The CRPD Committee has expressed concern at the insufficient incorporation and uneven implementation of the Convention across all policy areas and levels in the UK, including in the devolved administrations.² Failure to give legal effect to the CRPD means that the rights of d/Deaf and disabled people in NI will not be effectively realised.

² Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1

Measure

Action
Explore ways in which the CRPD can best be given legal effect in NI
Commission a legal scoping study to identify and compare benefits of and models for incorporation
In collaboration with d/Deaf and disabled people their organisations and IMNI ³ , develop proposals for consultation
Explore ways in which the CRPD can be given legal effect through a Northern Ireland Bill of Rights

2.2 Participation in policy design, implementation and monitoring

Issue

Deaf and disabled people in Northern Ireland are often excluded from the design, implementation and monitoring of laws and policies which affect their lives. This issue is not confined to the Disability Strategy but applies to all laws and policies which underpin and relate to the Strategy affecting d/Deaf and disabled people. Efforts to involve d/Deaf and disabled people in law and policy design, implementation and monitoring are often tokenistic, inaccessible, or exclude particularly marginalised groups, including sign language users, people with learning disabilities and people with experience of mental health services. The Disability Strategy, and all laws and policies

3 IMNI stands for Independent Mechanism for Northern Ireland. This is made up of the Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission (NIHRC)

which underpin it and flow from it, can act as a gold standard to demonstrate how meaningful participation of d/Deaf and disabled people can be achieved in design, implementation and monitoring.

Human Rights Obligations

Under Article 4(3) and 33(3) CRPD, States have an obligation to “closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations” in the development of legislation and policies to give effect to the CRPD, and in the monitoring framework to oversee progress in achieving the CRPD at the domestic level. The CRPD Committee has clarified in General Comment 7 that disabled people’s organisations (DPOs) “can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves.”⁴

The Committee notes that DPOs should be distinguished from organisations “for” persons with disabilities, “which provide services and/or advocate on behalf of persons with disabilities, which, in practice, may result in a conflict of interests.”⁵ General Comment 7 obliges States to build the capacity and empowerment of DPOs in particular and “ensure that priority is given to ascertaining their views in decision-making processes” especially the need to prioritise the views of DPOs over those of third party organisations advocating for disabled people. In fact, DPOs in Northern Ireland played a

⁴ Committee on the Rights of Persons with Disabilities (2018) General Comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention. UN: CRPD/C/GC/7, para 11

⁵ Ibid, para 13

crucial role in advocating for and shaping the content of General Comment 7 and should be central to its implementation in Northern Ireland.

Barriers

The absence of a Northern Ireland wide governance framework involving d/Deaf and disabled people and their organisations and their limited access to key decision making structures (in favour of third party organisations for disabled people) has been a persistent challenge in the development of policies and legislative measures that affect d/Deaf and disabled people. There is also a lack of perceived real engagement with d/Deaf and disabled people and their representative organisations by the Independent Monitoring Mechanism for Northern Ireland (IMNI) responsible for monitoring the progress of the implementation of the CRPD. The work of DPOs in Northern Ireland is hampered by a lack of core funding (that is, not specifically project based) and the creation and expansion of DPOs to strengthen their involvement in existing and future decision-making structures at a local and regional level drawing attention to the perceived greater number of DPOs prevalent in the rest of the UK.

There is evidence of some good practices in Northern Ireland and internationally which can be used to inform and further develop the measures proposed below. These include a commitment (yet to be delivered) by the Northern Ireland Executive in the Draft Executive Programme for Government 2016 to involve disabled people in the setting up of a “central regional disability forum”. The Independent Mechanism for Northern Ireland has fully committed to the development of an “IMNI Disability Forum” to directly engage d/Deaf and disabled people in the monitoring of the implementation of the CRPD. Terms of Reference for the

IMNI Disability Forum⁶ in consultation with DPOs and others have been drafted taking account of some key aspects of General Comment No. 7:

- Membership will principally be drawn from Disabled People-led Organisations and disability related NGOs who represent persons with disabilities and who have complementary expertise and experience.
- Due regard is also being paid toward ensuring that overall membership is weighted towards a majority (3/4 or higher) representation of persons with disabilities, with all organisations to be encouraged to put forward a person with a disability as their organisational representative.

The Office for Disability Issues in New Zealand (ODI) provides \$100,000 per year for the Disabled People's Organisations Coalition to meet regularly and engage with government agencies on the development and monitoring of New Zealand's Disability Action Plan, the primary vehicle for implementation of the New Zealand Disability Strategy 2016-2026 and thus the CRPD.

The Independent Monitoring Mechanism in New Zealand also includes the Disabled People's Organisations Coalition in monitoring implementation of the CRPD. The Government provides \$275,000 per year to fund the Disabled People's Organisations Coalition to provide disabled people-led monitoring. Other progressive features of the New Zealand good practice model ensure that disabled people are in the majority at the decision-making table and that the substantive agenda for engagement

6 Further information is available from Independent Mechanism for Northern Ireland, 'Disability Forum' (March 2020) <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI-DisabilityForum.pdf> 9 December 2020

with government officials and those from the independent mechanism is set by disabled people themselves.⁷

Measures

Action
Develop a Northern Ireland Disability Forum to work with government, with d/Deaf and disabled people in a leadership role
Work with women, girls, children and young people, older people, ethnic minorities, people with learning disabilities and mental health issues, d/Deaf people and others to ensure their direct participation and involvement in such a Forum
Prioritise the views of d/Deaf and disabled people and their representative organisations
Fund and support the operation of DPOs to engage effectively in decision making and support the expansion of DPOs across Northern Ireland
Fund d/Deaf and disabled people's participation in the monitoring framework using models of good practice elsewhere
Ensure that every Minister and senior civil servant has a copy of General Comment No. 7 and considers every consultation and engagement with d/Deaf and disabled people against the CRPD Committee's recommendations set out in paragraph 94

⁷ New Zealand Office for Disability Issues, 'UN Disability Experts Issue New Legal Guidance' (Office for Disability Issues, 14 November 2018) <https://www.odi.govt.nz/whats-happening/un-disability-experts-issue-new-legal-guidance-the-un-conventions-new-general-comment-number-7/> accessed 20 November 2020

Action

“Nothing about us without us” must be at the heart of any agreed Disability Strategy – d/Deaf and disabled people must agree with what is in any proposed Strategy

Consider all the recommendations in paragraph 94 of General Comment No. 7 and adopt most, if not all, of the recommendations put forward including recommendation (a) with regard to “legal capacity”.

2.3 Leadership and Governance of the Strategy

Issue

Effective implementation of a Disability Strategy requires clear leadership and governance, with involvement of all relevant parties. Leadership can be expressed in diverse ways, ranging from demonstrating commitment to achieving change and positive impact through to establishing clear structures to oversee implementation and monitoring of the strategy, and providing ongoing feedback to d/Deaf and disabled people and their organisations over the lifetime of the strategy.

Measures

Action

Ensure that Departmental leads are clearly identified

Clear structures to oversee implementation and monitoring of the strategy should be established in advance of the Strategy’s commencement

Action

Monitoring oversight by a Northern Ireland Disability Forum. This group should meet on a quarterly basis – these meetings may include informal group discussions

A pre-meeting should be held at departmental level, consisting of departments only, in advance of each formal Forum meeting to facilitate an update to the Forum on actions relating to the Disability Strategy

Ensure DPOs have a meaningful leadership role in conjunction with recommendations set out in the section on Participation, and that this includes people with learning disabilities, who are d/Deaf, d/Deaf and disabled children, disabled older people, and those from particularly marginalised groups

The Strategy lead department should have the power to ensure co-operation across departments in respect of Strategy actions

All departments should have a clearly identified lead person responsible for taking forward Strategy implementation and monitoring therein

2.4 Transparency and Accountability

Issue

Transparency and accountability are critical success factors in realising the aims of national disability strategies.⁸ Reporting on the extent to which progress is being made requires availability of relevant, up to date and accessible information. Deaf and disabled people and their representative organisations must be able to follow progress in a timely and accessible manner, and be able to provide feedback on strategy developments.

⁸ Eilionóir Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011)

Measures

Action
Deaf and disabled people and their representative organisations should be involved in all aspects of implementation and monitoring (see Participation section above)
All appointments to Strategy implementation and monitoring structures should be conducted in transparent manner
Publication of full membership of all Strategy implementation and monitoring structures
Minutes should be taken at all meetings conducted in relation to the Disability Strategy
All minutes of formal meetings should be made publicly available online and in accessible formats
A Progress Report should be completed each year by the lead department for consideration by the Northern Ireland Disability Forum. This should provide an update on all actions taken across departments and progress against agreed indicators
The Progress Report should be made publicly available and in accessible formats.

2.5 Resources

Issue

Effective implementation of a Disability Strategy requires the allocation of adequate human and financial resources. This requires an alignment of current resources with expected outcomes and the allocation of additional strategy specific resources, as required.

Human Rights Obligations

Article 4(2) of the CRPD makes it clear that, with regard to economic, social and cultural rights, each State party must take measures to the maximum of its available resources and, where needed, subject to progressive realisation. This remains the case even where there are challenges to or limited resources. This means there must be continual progress.

Barriers

If no additional resources are allocated to the Disability Strategy this will make achievement of its objectives hugely challenging and restrict the extent to which this can be meaningful.

In its 2017 recommendations to the UK, the CRPD Committee expressed concern at the challenges facing organisations of d/Deaf and disabled people in accessing support and being consulted and actively involved in the implementation of the Convention.⁹ The Committee recommended the UK allocate financial resources to support organisations representing persons with disabilities, including women and children with disabilities, and develop mechanisms to ensure the inclusive, strategic and active involvement of

⁹ Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1

organisations of persons with disabilities, in the planning and implementation of all measures that affect the lives of persons with disabilities. This extends to involvement in the development, implementation and monitoring of the CRPD.

The CRPD Committee also expressed concern about the lack of resources available for the effective and comprehensive monitoring by the UK Independent Mechanism (including the Independent Mechanism for NI) under Article 33(2) CRPD.¹⁰ The Committee acknowledged that this limits the support provided to organisations of persons with disabilities to participate in the monitoring process. This monitoring role extends to monitoring the development and implementation of the Disability Strategy.

Measures

Action
Ensure that the Disability Strategy and its actions are appropriately resourced
Ensure that additional resource allocations are made where necessary for achievement of objectives
Ensure organisations of d/Deaf and disabled people are adequately resourced to facilitate inclusion in the development, implementation and monitoring of the Disability Strategy
Ensure IMNI is adequately resourced to fulfil its role under Article 33 CRPD, including for monitoring of the Disability Strategy
Ensure the Disability Strategy is resourced for its entire duration through ring fenced funding for each of the strategy actions

10 Ibid

Action

Adopt a human rights-based approach to budgeting by making sure d/Deaf and disabled people are visible and taken into account in budget related documentation and throughout the budget process

2.6 Data collection and indicators

Issue

Without data, laws and policies cannot be effectively developed, implemented or monitored. Data collection is not a one-off exercise. Across the areas proposed in this report, the panel has been concerned at the lack of ongoing and robust disaggregated quantitative and qualitative data on (i) the lived experiences of d/Deaf and disabled people and (ii) on the implementation and evaluation of laws, policies and practices relating to d/Deaf and disabled people across the life course.

Human Rights Obligations

Human rights indicators on the CRPD are key to facilitating understanding and implementation of the Convention's provisions. Article 31 CRPD requires all States Parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the CRPD. This is critical for all the topics covered in this report.

The importance of data collection has been reinforced by other human rights treaties and treaty bodies such as the UN Committee on the Rights of the Child ¹¹ which has called on States Parties to utilise an appropriate definition that guarantees the inclusion of all children with disabilities so that children with disabilities may benefit from the relevant policies, programmes and services. Moreover, that establishing effective mechanisms for data collection has an impact on the types of measures that need to be taken and on the distribution of the resources needed to fund programmes.

Barriers

The CRPD Committee has expressed concern at the lack of a unified data-collection system and indicators across the UK concerning the situation of persons with disabilities. It has noted the limited collection of disaggregated data in surveys and censuses on the general population.¹²

It is not always clear what data currently exists and where and how it can be accessed. The CRC Committee, for example, has highlighted that one of the main challenges in obtaining accurate statistics is the lack of a widely accepted clear definition for ‘disability’.

¹¹ See also, for example, UN Office of the High Commissioner on Human Rights, ‘A Human Rights Based Approach to Data: Leaving no one behind in the 2030 agenda for sustainable development’ (2018) <https://www.ohchr.org/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf> accessed 10 December 2020

¹² Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1

Measures

The Office of the High Commissioner on Human Rights (OHCHR) has developed human rights indicators on the CRPD as a key tool to facilitate understanding and implementation of the Convention's provisions.¹³ The Disability Strategy should adopt these indicators as a means of monitoring progress across the strategy timeframe and to enable comparison across time periods and countries.

Action

Ensure collection, and increase availability, of high-quality, timely and reliable disaggregated quantitative and qualitative data, including in all general population surveys and censuses and that recognises the diversity and intersectionality of disability

Adopt OHCHR CRPD human rights indicators and ensure these are used across Government departments and agencies to monitor d/Deaf and disabled people's experiences of their rights

Ensure that data collected on disability is inclusive, adopts a rights-based definition of disability and enables d/Deaf and disabled people to self-identify

Deaf and disabled people, including d/Deaf and disabled children, and their representative organisations, should be involved in deciding what data should be collected

13 UN Office of the High Commissioner on Human Rights, 'Human Rights Indicators on the UN Convention on the Rights of Persons with Disabilities in support of a disability inclusive 2030 agenda for sustainable development' (OHCHR, 2020) <https://www.ohchr.org/EN/Issues/Disability/Pages/SDG-CRPDindicators.aspx> accessed 4 December 2020

2.7 Awareness-Raising

Issue

While a commitment to awareness raising was included in the previous Disability Strategy this did not include clear actions or targets.

Human Rights Obligation

Article 8 of the CRPD sets out the obligation on States to undertake to adopt ‘immediate, effective and appropriate measures’ to raise awareness, foster respect for the right and dignity of d/Deaf and disabled people, combat negative stereotypes and prejudices, and to promote awareness of the capabilities and contributions of d/Deaf and disabled people.

Barriers

In 2017, the CRPD Committee expressed concern at the persistence of negative attitudes, stereotypes and prejudice against persons with disabilities, particularly persons with learning and/or psychosocial disabilities and persons with neurological and cognitive conditions such as dementia and Alzheimer’s, and about their social protection entitlements.¹⁴

¹⁴ Committee on the Rights of Persons with Disabilities, ‘Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland’ (UN 2017) CRPD/C/GBR/CO/1

In 2018/19, there were 53 recorded disability motivated hate crimes.¹⁵ The UK Independent Mechanism believes the number of reported incidents significantly under-represents the extent of disability hate crime throughout the UK, including in Northern Ireland.¹⁶

Measures

Action
Develop key awareness-raising actions, for example, public awareness strategies and campaigns with different target audience groups based on the human rights-based approach to disability
Continue to raise awareness of, and challenge, disability hate crime
Promote disability awareness throughout all levels of the education system from an early age
Include disability awareness in pre-school, primary and secondary school curriculums

15 PSNI, ‘Trends in Hate Motivated Incidents and Crimes Recorded by the Police in Northern Ireland 2009/10 to 2018/19’ (PSNI, 2019)

16 UK Independent Mechanism Parallel Report to the CRPD Committee, ‘Disability rights in the UK’, (2017) p. 44

2.8 Strategy Duration

Issue

If the Disability Strategy is to be effective it should be time bound and set real and achievable targets across this duration.

Measures

Action
The panel recommends that the Disability Strategy cover a 5-year period focusing on priority actions with an in-built review at the midway point. An annual Progress Report should be provided to the Northern Ireland Disability Forum as the overarching monitoring body and made publicly available and accessible

3.0 Autonomy and Independent Living

3.1 Legal Capacity

Issue

Deaf and disabled people in Northern Ireland continue to face barriers in exercising their legal capacity, notwithstanding the enactment of the Mental Capacity Act 2016. This Act is not compliant with Article 12 of the CRPD as interpreted by the UN Committee on the Rights of Persons with Disabilities in General Comment No. 1¹⁷, as it continues to provide for substituted decision-making based on an assessment of mental capacity for those who have ‘an impairment or disturbance in the functioning of the mind or brain.’

Furthermore, the Act has only been partially commenced (in relation to serious interventions and deprivation of liberty) – therefore none of the less restrictive options under the Act are currently available to d/Deaf and disabled people, and the 1986 Mental Health Order is still running in parallel to the new legislation.

Human Rights Obligations

The CRPD Committee’s Concluding Observations on the UK, issued in 2017, required the abolition of “all forms of substituted decision-making concerning all spheres and areas of life by reviewing and adopting new

¹⁷ 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

legislation.”¹⁸ This demonstrates that the CRPD Committee does not find that the 2016 Act is compatible with the requirements of Article 12. In General Comment No. 1, the Committee requires states to have respect for will and preferences and to replace best interests determinations in decision-making (at least in respect of disabled adults).

The General Comment also requires legal recognition of the support person(s) formally chosen by a person to be available and accessible, and States have an obligation to facilitate the creation of support, particularly for people who are isolated and may not have access to naturally occurring support in the community. This must include a mechanism for third parties to verify the identity of a support person as well as a mechanism for third parties to challenge the action of a support person if they believe that the support person is not acting in accordance with the will and preferences of the person concerned.

In order to comply with the requirement, set out in Article 12, paragraph 3, of the Convention, for States Parties to take measures to “provide access” to the support required, States parties must ensure that support is available at nominal or no cost to d/Deaf and disabled people and that lack of financial resources is not a barrier to accessing support in the exercise of legal capacity. The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity.

18 Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1

Barriers

The 2016 Act, which has not been fully commenced, continues to provide for substituted decision-making, with no legal recognition of specific support options. The more supportive elements of the Act, including the availability of a nominated person, lasting powers of attorney, and advance decisions – are all still predicated on assessments of mental capacity, contrary to General Comment No. 1.

Independent mental capacity advocates are currently in place in some health trusts, funded by the State, but it is not clear whether these are now available in all health trusts, which means that d/Deaf and disabled people may not have access to this support to challenge decisions made about them where they are deemed to lack capacity. Furthermore, the Act does not provide any legal recognition of the capacity, or supports available for children under 16. Deaf and disabled people have insufficient practical opportunities to access support to exercise legal capacity (due in part to a lack of State funding for grassroots initiatives designed and led by d/Deaf and disabled people, or initiatives not being sufficiently recognised by third parties or the State where they do exist).

The Act also continues to provide for determinations of unfitness to plead and the defence of insanity, both of which represent disability-based discrimination according to the UN Committee on the Rights of Persons with Disabilities. Furthermore, the Sexual Offences (Northern Ireland) Order 2008 introduced a series of specific sexual offences against persons with mental disorder, which to some extent mirror the specific sexual offences against children. Adults with disabilities – including those with cognitive disabilities, should not be treated like children in laws on sexual consent, and the UN Committee has been critical of the existence of disability-specific offences.

Action

Repeal and replace the 2016 Act with legislation which replaces substituted decision-making based on best interests with supported decision-making in line with the person's will and preferences

Develop legislation which recognises that children under 16 (including disabled children) can exercise legal capacity with support

Commence law reform processes on other issues related to legal capacity to ensure equal recognition for d/Deaf and disabled people (e.g. consent to sex)

Provide state funding for grassroots supported decision-making initiatives led by d/Deaf and disabled people

Develop a virtual 'one-stop shop' where d/Deaf and disabled people in NI can access information about support to exercise legal capacity in all aspects of life (including a list of all services currently providing independent mental capacity advocates)

Design regulations (with the active participation of d/Deaf and disabled people) specifying different support options which d/Deaf and disabled people over 16 can access to exercise legal capacity (flowing from section 5 of 2016 Act)

Produce guidance for third parties in different sectors (e.g. banking/finance, health and social care, etc) on how to respect the legal capacity of d/Deaf and disabled people and ensure they have the desired access to support to exercise legal capacity

3.2 Independent Living, Adequate Standard of Living and Social Protection

Issue

For many d/Deaf and disabled people in Northern Ireland the concept of living independently is more a “pipe dream” than a reality, particularly for those with complex support requirements and others who are past retirement age. Young people are also finding themselves living in care homes rather than with their peers at the heart of the community. The closure of the Independent Living Fund from June 2010 to any new applicants has severely limited d/Deaf and disabled people’s choice and control and independence. The availability of accessible and affordable housing for people with a range of disabilities continues to be a significant issue (ranging from suitable supported living accommodation to making adaptations to the home).¹⁹

19 DSD/DHSSPS, Inter-Departmental Review of Housing Adaptations Services: Final Report and Action Plan 2016 and consider ongoing gaps not addressed in both the social and private sector beyond the review such as homelessness and allocation and entitlement to social housing <https://www.nihe.gov.uk/Documents/Adaptations-services-review/housing-adaptations-review-final-report.aspx> accessed 14 November 2020. See also Northern Ireland Homeless Bulletin, Department for Communities (March 2019) <https://www.communities-ni.gov.uk/system/files/publications/communities/ni-homelessness-bulletin-apr-sep-2018.PDF> accessed 20 November 2020

Human Rights Obligations

Under Article 19 of the CRPD, government must “recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, taking effective and appropriate measures to ensure their full inclusion and participation in the community.” This should include “the opportunity to choose their place of residence and where and with whom they live on an equal basis with others” and government must ensure that d/Deaf and disabled people “are not obliged to live in a particular living arrangement; have access to a range of in-home, residential and other community responsive support services, including personal assistance necessary to support living and inclusion in the community, to prevent isolation or segregation from the community.”

In General Comment No. 5, the CRPD Committee have highlighted the fact that persons with disabilities have historically been denied their personal and individual choice and control across all areas of their lives. Many have been presumed to be unable to live independently in their self-chosen communities. Support is either unavailable or tied to particular living arrangements, resources are invested in institutions instead of supporting people to live independently in the community. This has led to abandonment, dependence on family, institutionalisation, isolation and segregation. Drawing upon the fact that many d/Deaf and disabled people live in poverty, the Committee has asked government to acknowledge that the cost of social exclusion is high as it perpetuates dependency and thus interference with individual freedoms. Social exclusion also engenders stigma, segregation and discrimination, which can lead to violence, exploitation and abuse in addition to negative stereotypes that feed into a cycle of marginalisation of persons with disabilities. Policies and concrete plans of action for social inclusion, including through the promotion of their right to independent living (Article 19), represent a cost-effective mechanism to ensure the enjoyment of rights, sustainable development and a reduction in poverty.

Barriers

Northern Ireland lacks standalone legislation guaranteeing the right to independent living and a dedicated strategy on independent living. The Physical and Sensory Disability Strategy and the Bamford Review and Action Plan have concluded and there is no evidence of any new strategy or action plan to specifically address this issue.

The roll out of Self Directed Support as a true model for choice and control for d/Deaf and disabled people in Northern Ireland has been limited and remains in the early stages of development. There is also a need to reform Adult Social Care to enhance the independence of d/Deaf and disabled people.²⁰ Further engagement with the Independent Living Fund (ILF) Working Group, taking account of the views of d/Deaf and disabled people and carer's ILF Scotland Consultation Report of Survey which was completed on 30th June 2020, would also be useful to explore options on re-opening the ILF to new applicants in Northern Ireland.

20 See Des Kelly and John Kennedy, 'Power to People: proposals to reboot adult care and support in NI' (Department of Health, 2017) <https://www.health-ni.gov.uk/sites/default/files/publications/health/power-to-people-full-report.PDF> accessed 10 December 2020

Many d/Deaf and disabled people in Northern Ireland (especially people with learning disabilities and people with experience of the mental health services) are still living in residential care homes and other institutional settings; (see section on institutionalisation in this report). Welfare cuts also have had adverse impacts on independent living opportunities as detailed in the welfare reform section of this report. Finally, budget cuts to public services including accessible and affordable community transport in urban and rural areas all undermine the priority that should be given to making independent living a reality for all d/Deaf and disabled people.

Measures

Action
Adopt any final recommendations from the ILF Work Group including agreed options and terms for reopening the Independent Living Fund to new applicants
Recommendations for the improvement of the operation of ILF taking account of experience of ILF recipients
Consider Recommendations of “Power to People Report” – in particular the human rights approach proposed in reform of adult social care
New build of Life Time Homes in operating updates in inclusive design in the Social Housing Sector and incentivise accessibility adaptation in existing private housing stock
Review the legislative framework for housing and the definition of “homelessness” (including in the recently announced Interdepartmental Homelessness Action Plan) to be revised to consider the accessibility of properties as the criteria for securing maximum points on the waiting list for priority housing

Action

Recognise personal assistants as distinct from carers in adult social care, and ensure they are available to all d/Deaf and disabled people especially marginalised groups including people with learning disabilities and people who have experience of mental health services

Promote and facilitate the use of self directed support and direct payments including accessible information to ensure all d/Deaf and disabled people can access and use these options

3.3 Welfare Reform

Issue

Deaf and disabled people have been disproportionately affected by the welfare reforms to the social security system in Northern Ireland. These include the introduction of Universal Credit to replace six main benefits and credits (including Jobseekers Allowance), replacement of the Disability Living Allowance with the Personal Independence Payment; reform of Housing Benefit, introduction of an under-occupancy penalty better known as the “bedroom tax; changes to child support and a new “claimant commitment” criteria (sanctions regime) containing stronger penalties for fraud and error.

Human Rights Obligations

In 2016, the CRPD Committee conducted an investigation examining the austerity measures (including welfare reforms) in the UK including Northern Ireland and concluded that there “was reliable evidence that the threshold of grave and systemic violation of the rights with people with disabilities

had been met by the State party.”²¹ The CRPD Committee reviewed evidence from d/Deaf and disabled people across the UK that showed d/Deaf and disabled people are significantly disproportionately adversely impacted by the welfare reforms including:

- lower income for households with disabled people claiming benefits under the new welfare system
- disabled people being the biggest single group adversely affected by the welfare reforms
- more disabled people living in poverty
- no account being taken of those people no longer eligible for benefit entitlements and services
- risk of social isolation and more reliance on informal and family care
- loss of eligibility for or reduction in entitlement under the assessment for the Personal Independence Payment
- the negative impacts of the reduction on housing benefits

21 Committee on the Rights of Persons with Disabilities (2017) Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention. CRPD/C/15/4 <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/326/14/PDF/G1732614.pdf?OpenElement> accessed 20 November 2020

- no human rights model considered within the assessment processes associated with the transitional arrangements associated with the abolition of the Disability Living Allowance and the introduction of the new Personal Independence Payment; or Employment Support Allowance and associated Work Capability Assessments
- adverse impact on public transport services available for disabled people; and the negative stereotyping of disabled people

Barriers

Social security matters are devolved to the Northern Ireland Assembly, however the Northern Ireland Executive has not been able to comprehensively develop its own approach to welfare provision in Northern Ireland including for d/Deaf and disabled people due to what is referred to as the 'parity principle'. As part of "A Fresh Start, the Stormont Agreement and Implementation Plan", the Northern Ireland Executive set out an agreed approach to implementing welfare reform in Northern Ireland. That included the allocation of £585 million from Executive funds (the block grant) to 'top up' UK welfare arrangements in Northern Ireland. That funding was for a four-year period from 2016/17 through to the 2019/20 financial year to mitigate against, temporarily at least, some of the worst cuts to our social security benefits.

A Welfare Reform Mitigations Working Group was established, led by Professor Eileen Evason, to develop recommendations most of which have been implemented, but these do not adequately address all of the issues facing d/Deaf and disabled people.²² The Welfare Reform Mitigations Working Group recommended the introduction of two further schemes that have not yet been provided for in secondary legislation. Those were the Cost of Work Allowance and a Contingency Fund for Universal Credit claimants. According to the Department for Communities, any decision to continue with welfare mitigations would not only require the allocation of further substantial funding but would also require new legislation.²³ The Department for Communities has given a commitment to undertake a cumulative impact assessment of the impacts of welfare reforms this year, however the Panel would like to draw attention to the Welsh and Scottish governments commissioned programmes of research between 2012 and 2015, assessing the impact of welfare reforms across their jurisdictions.

22 See Eileen Evason and Kevin Higgins, ‘Report on the welfare mitigation programme designed to lessen the impact of the harshest aspects of the system in Northern Ireland’ (Child Poverty Action Group, 1 October 2019) <https://cpag.org.uk/sites/default/files/files/CPAG-Poverty164-Welfare-reform-mitigation-Northern-Ireland.pdf> accessed 14 November 2020. See also Welfare Reform Group Mitigation’s Report (Northern Ireland Council for Voluntary Action, January 2016) <https://www.executiveoffice-ni.gov.uk/publications/welfare-reform-mitigations-working-group-report> accessed 10 December 2020

23 Department for Communities, Review of Welfare Mitigation Schemes (March 2019) <https://www.communities-ni.gov.uk/system/files/publications/communities/dfc-review-of-welfare-mitigation-schemes-2019.pdf> accessed 10 December 2020

These found that families with dependent children and claimants with health problems and disabilities are hit the hardest financially by the welfare reforms.

The Scottish Government A Human Rights Approach to Social Security: stretching the “principle of parity” adopting the general principle of dignity

The authors of the Northern Ireland Human Rights Commission’s Cumulative Impact Assessment of Tax and Social Security Reforms November 2019 report²⁴ recommended that the Northern Ireland Executive adopt Scotland’s approach, wherein it recognises and takes a legislatively grounded rights-based approach to social security. Their report drew particular attention to the Scottish Human Rights Commission observation that the seven core principles embedded in Scottish social security law in 2018 deliberately corresponded to some of the fundamental aspects of the right to social security, as set out in key human rights instruments such as the International Covenant on Economic, Social and Cultural Rights, the Universal Declaration of Human Rights and the European Social Charter. The Scottish social security principles are: social security is an investment in the people of Scotland; social security is itself a human right and essential to the realisation of other human rights; respect for the dignity of individuals is to be at the heart of the Scottish social security system; the Scottish social security system is to be designed with the people of Scotland on the basis of evidence; that opportunities be sought to continuously improve the Scottish social security system in ways which put the needs of those who require assistance first, and advance equality and non-discrimination as well as

24 Northern Ireland Human Rights Commission, ‘Cumulative Impact Assessment of Tax and Social Security Reforms’ (NIHRC, November 2019).accessed 11 December 2020 https://www.nihrc.org/uploads/publications/Final_CIA_report_Oct_2019.pdf

value for money.²⁵ As the Independent Mechanism for Northern Ireland highlighted, the principles enshrined in the Social Security Scotland Act 2018 also apply to the assessment process. The legislation provides for a restriction of assessments of applicants by ensuring that the individuals carrying out the assessments are in the employment of a public body. Moreover, a consultation with the applicant is only conducted when it is the only practical means to obtain evidence to support the individual's application. The principles themselves do not explicitly comply with the UN Committee's recommendations; but by recognising social security as a human right, which is also essential to the realisation of other human rights, it therefore ensures a rights-based approach to social security.²⁶

The Panel also noted that during the preparation and drafting of this report that the Personal Independence Payment legislation is to be repealed by the Scottish Government as announced on 23rd October 2020, undoubtedly born of government's desire to reflect the human rights principles outlined above, underpinning social security legislation. Among the key changes in the alternative legislation are; the removal of medically based functionality type based assessments and the removal of private sector involvement in determining entitlement of individuals to disability related benefits.

25 Social Security (Scotland) Bill - Policy Position Paper: Social Security Principles and a Rights Based Approach, (20 September 2017) accessed 12 December 2020 <https://www.gov.scot/publications/social-security-principles-and-a-rights-based-approach/>

26 Independent Mechanism for Northern Ireland, 'Report on the Department for Communities Response to the Independent Review of PIP Process and Compliance with Recommendations of the UNCRPD Committee' (IMNI, 3 July 2019), https://www.nihrc.org/uploads/publications/PIP_in_NI_IMNI-03.07.2019.pdf accessed 10 December 2020

Shirley-Anne Somerville, Cabinet Secretary for Social Security and Older People for Scotland, said no one should ever experience stress when accessing the support they are entitled to. “Getting rid of degrading assessments that our Experience Panels told us were ‘traumatic and intrusive’ is the right thing to do. It is an obvious change but one that will make a massive difference to people.”²⁷

Research by the Right to Work: Right to Welfare Group at Participation and the Practice of Rights (PPR) monitored the impact of sanctions over three years. PPR noted through a Freedom of Information response regarding sanctions or ‘adverse decisions’ relating to people accessing Employment and Support Allowance (ESA) 13, 609 ‘adverse decisions’ were made to remove people’s entitlement to ESA. They found that sanctions were imposed upon claimants without due process or protection from destitution, further demonstrating that sanctions are being used against d/Deaf and disabled people. Deaf and disabled people have asked for these sanctions to stop.²⁸

“We are Right to Work; Right to Welfare” - a group of sick and disabled unemployed people campaigning for simple, but potentially life changing, changes in how public money is spent, jobs are created and social security is administered. “We are amazed by the polite civility of the ‘Cash for Ash’

²⁷ Stewart Paterson, “‘Degrading’ PIP and DLA style assessments to be scrapped for new Scottish Adult Disability Payment’ Glasgow Times, 23 October 2019

²⁸ Participation and the Practice of Rights (PPR), Right to Work: Right to Welfare Group, Cruelty: Social Security, the Economy and Human Rights’ (October 2018) <https://www.pprproject.org/resource-document/conscious-cruelty-final-report> accessed 12 December 2020

inquiry compared to the hostile enquiries sick, disabled and unemployed people are subjected to daily as citizens try to claim their benefits. We also note that claimants for JSA, ESA and PIP do not have the luxury of giving answers such as ‘I do not recall’, ‘I was not aware’, ‘that is not my recollection’ or ‘in hindsight I would have done that differently’.

These are the acceptable replies of the top benefit claimers like SPADs and Ministers. This is the story of the sick, disabled and unemployed people who are subjected to these enquiries which run rough shod over their rights, strip them of their dignity, cost so much, achieve so little and benefit only private companies. This has to stop.”

The PPR Group made a range of proposals that the NI Executive could implement to deal with the issues. These included due process, improvements to the Work Capability Assessments and a robust risk assessment before implementing any sanctions. More recent reports from the Equality and Human Rights Commission in Great Britain showed as more d/Deaf and disabled people were sanctioned, there was a corresponding increase in the number of disabled people not in work. Furthermore ESA claimants who were sanctioned were less likely to gain employment in later months. The UK Government’s policy to intensify the use of sanctions and introduce harsher penalties has been largely ineffective at moving people into sustainable employment. Benefit sanctions had no tangible positive effects in moving disabled people closer to paid work and worsened many disabled people’s illnesses and impairments, particularly mental health

conditions.²⁹ Evidence to the CRPD Committee from d/Deaf and disabled people in Northern Ireland highlighted the fact that d/Deaf and disabled people had been sanctioned on mandatory work programmes they were not even aware that they were on, and that often the information telling them what they were required to do was not accessible. The submission concluded that frontline staff delivering social security had a clear lack of knowledge of the risks associated with implementing sanctions.³⁰

Action

Repeal the PIP benefit and associated assessment for a better alternative, based on the social security legislation in Scotland adopting human rights principles underlining that legislation

Repeal the Work Capability legislation, including the associated assessment and adopt a human rights approach to supporting disabled people into employment that does not conflict with their right to an adequate standard of living and entitlement to social security

29 Participation and the Practice of Rights (PPR), Right to Work: Right to Welfare Group, Campaign Issue in Focus Social Security Sanctions in Northern Ireland, (2016) <https://www.pprproject.org/campaign-issue-in-focus-social-security-sanctions-in-northern-ireland> accessed on 12 December 2020

30 Disability Action Northern Ireland Alternative Report on the Implementation of the UNCRPD (2017) <https://www.disabilityaction.org/Handlers/Download.ashx?IDMF=1e54332c-73c8-47bc-bd4f-65d616fb77fd> accessed on 12 December 2020

Action

The Scottish Government engaged meaningfully and directly with d/Deaf and disabled people through establishing “disability experience panels”, and have begun developing a social security system intended to reflect those experiences in keeping with CRPD obligations. The Northern Ireland Government must reflect this human rights approach that affords dignity and autonomy to d/Deaf and disabled people in the development of future social security provision

Consider the abolition of Universal Credit in light of its disproportionate adverse impact on d/Deaf and disabled people and its replacement with a social security system that is compatible with a human rights approach in line with the recommendations above

Extend and maintain the existing welfare mitigations package

Extend the scope for further mitigations, including the introduction of the Contingency Fund to support those on Universal Credit.

Exclude d/Deaf and disabled people, children and families from the sanctions regime associated with Universal Credit

Research to consider the impact of welfare reforms on specific disability grounds e.g. mental health issues/d/Deaf people

Adopt the recommendations from the British Deaf Association for a separate benefit for d/Deaf people to access language interpretation services; retention of the Covid 19 measure - £20 increase for claimants on Universal Credit

Amend the payment schedule associated with Universal Credit for d/Deaf and disabled people in line with fixed day fortnightly benefits of Employment Support Allowance and income support

Action

New claimants on Universal Credit should be entitled to severe disability premiums on the same basis of eligibility and entitlement guaranteed in the legacy benefit system

A supplementary payment should be made available to mitigate the loss of disability premiums for children transferring from DLA to PIP

Remove private contracts in the delivery of social security as adopted by the Scottish government in the new social security legislation hitherto previously referred in earlier recommendations, and evaluate the economic benefits from this approach to the existing one

Advance payments to support d/Deaf and disabled people making an initial claim on Universal Credit should be provided in the form of a non-repayable grant

The discretionary support service should extend grant payments rather than loans to d/Deaf and disabled people on low income in particular for those d/Deaf and disabled people not entitled to other disability related benefits

Restore the value of Carers' Allowance to 2010 levels

Restore the Sure Start maternity grant to all d/Deaf and disabled babies whose parents have low income

Develop a childcare strategy which includes priority consideration for the additional costs to childcare providers of caring for a disabled child

Remove the two child limit which takes account of General Comment No. 3, Article 6 - Women and Girls with Disabilities (adopted 26 August 2016)

Provide support needed by d/Deaf and disabled people to access appeals and complaints mechanisms related to social security entitlements and enforce effective remedies for any breach of entitlements identified

3.4 Deinstitutionalisation

Issue

The abuse of d/Deaf and disabled people occurring at Muckamore Abbey Hospital (MAH) which came to light in 2017 shocked many across these islands and around the world. The scale of abuse uncovered was staggering, with a reported 1500 incidents of abuse on one ward alone subject to ongoing investigation³¹. Since then internal reviews³², criminal investigations³³ and latterly a public inquiry have been announced³⁴.

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- 31** Seanín Graham, 'Muckamore Abbey Hospital: 1,500 crimes identified in just one ward' Irish News, (27 August 2019) <https://www.irishnews.com/news/northernirelandnews/2019/08/27/news/1-500-crimes-have-been-identified-in-muckamore-abbey-hospital-abuse-scandal---in-relation-to-just-one-ward--1695200/> accessed 11 December 2020
- 32** A Review of Leadership and Governance at Muckamore Abbey Hospital, The Muckamore Abbey Review Team, (July 2020) <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-mah-review.pdf> accessed 10 December 2020
- 33** Seanín Graham, 'Police probing more than 70 allegations of 'ill treatment' at Muckamore hospital' Irish News, (15 August 2018) <https://www.irishnews.com/news/2018/08/15/news/psni-reveal-investigation-into-more-than-70-incidents-linked-to-abuse-probe-at-co-antrim-hospital-1407929/> accessed 10 December 2020
- 34** Department of Health, 'Swann announces Public Inquiry into Muckamore Abbey Hospital' (Department of Health, 8 September 2020) <https://www.health-ni.gov.uk/news/swann-announces-public-inquiry-muckamore-abbey-hospital> accessed 10 December 2020
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It is important to note how contextually these specific events have shone a much needed spotlight on a matter many members of the public were completely unaware of; in Northern Ireland in the 21st Century, long term institutionalisation of d/Deaf and disabled people remains a shameful ongoing reality.

The European Expert Group on the Transition from Institutional to Community-based Care³⁵ (EEG) defines institutionalisation in residential settings as where:

- residents are isolated from the broader community and/or compelled to live together
- residents do not have enough control over their lives and over decisions which affect them
- requirements of the organisation itself tend to take precedence over the residents' individual needs

On these terms, it is clear that institutionalisation is occurring in a widespread manner beyond the confines of hospital settings such as Muckamore et al in NI. This is also by no means unique to NI; at a European level estimates suggest that up to 1,438,696 people are living in institutions and that this number has remained largely unchanged in the last decade.³⁶

35 Jan Šiška, and Julie Beadle-Brown, Report on the Transition from Institutional Care to Community-Based Services in 27 EU Member States (European Expert Group on Transition from Institutional to Community-based Care, 2020) <https://deinstitutionalisationdotcom.files.wordpress.com/2020/05/eeg-di-report-2020-1.pdf> (10 December 2020)

36 Ibid, 5

These historic and ongoing inequalities have also been exacerbated by the emergence of our global pandemic, with institutional settings by their very nature being exceptionally vulnerable to COVID 19 outbreak and spread. It has been estimated that between 30 – 60% of all COVID deaths across Europe have been attributable to long term care facilities.³⁷

Human Rights Obligations

Domestically in NI the principal protections for d/Deaf and disabled people institutionalised or at risk of same sit within the provisions of the Human Rights Act (1998)³⁸ which incorporates the European Convention on Human Rights (ECHR) into domestic legislation. Key protections are contained in Article 3 - ‘Freedom from inhuman and degrading treatment’³⁹ and Article 8 - ‘Respect for private and family life’⁴⁰

Alongside the provisions of ECHR, another key protection at international level is found under Article 19 of the CRPD:

³⁷ ECDC Public Health Emergency Team et al, ‘High impact of COVID-19 in long-term care facilities, suggestion for monitoring in the EU/EEA, May 2020’ European Surveillance 25(22) European Surveillance 4 June 2020 <https://www.eurosurveillance.org/content/10.2807/1560-7917.ES.2020.25.22.2000956> accessed 11 December 2020

³⁸ Human Rights Act (1998)

³⁹ European Convention on Human Rights, Article 3

⁴⁰ Article 8

‘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.’⁴¹

Barriers

Insufficient data is available on a broad range of contributing factors to deinstitutionalisation. This includes, but is not limited to, numbers detained not just in long stay hospitals and larger scale institutional settings but also smaller scale community settings where institutionalisation is a reality. Policy over many years has been shaped too much by short term financial cost implications and not considering the wider long term financial gain from person centred community care settings. The fatalist framing of those with a learning disability being a burden, beyond help or support and something merely to be managed, has been the historic driver that has led to ‘warehousing’. In recent years it has been argued that d/Deaf and disabled people are facing a return to mass institutionalisation through ongoing regression and cuts to services.⁴²

⁴¹ United Nations Convention on the Rights of Persons with Disabilities, Article 19

⁴² Robin Jackson, ‘Back to Bedlam What Kind Of Future Faces People With A Learning Disability?’ (Centre for Welfare Reform, 2017) <https://www.centreforwelfarereform.org/uploads/attachment/582/back-to-bedlam.pdf> 10 December 2020

Measures

Action
Place those d/Deaf and disabled people currently institutionalised at the heart of all planning and decision making about their future
Establish an external independent review of the joint protocol mechanism. Assess what areas need to be strengthened, changed or abolished
Commit to a timetable/ resourcing for same
Ensure appropriate funding and provision of high quality independent advocacy provision to support those who need it
Funding should be sourced centrally and not from within specific departments
Resource and timetable the closure of all remaining long stay hospitals within Northern Ireland
Plan and resource community-based person- centred care to replace closed institutions. Replicate existing models of good practice and avoid pitfalls of merely transferring ‘institutional culture and practice’
Establish clear ring-fenced funding to ensure d/Deaf and disabled people can have the adaptations needed to continue to have choice and control of their lives once deinstitutionalised and moved to community settings
Value the contributions of staff who work in these areas. Recognise the challenges faced, support them to change culture, custom and practice
Model the existing good practice and upscale it

Action

Commit to establishing a clear protocol for the gathering and publication of data in respect of medications prescribed/ over-prescribed in large and small scale settings

Commit to data gathering and publication on both PRN (pro re nata – the administration of medication as needed, rather than as a regular dosage) and MAPA (Management of Actual and Potential Aggression) intervention use

Research and resourcing a systemic move to therapeutic interventions

3.5 Right to Liberty

Issue

Deaf and disabled people in Northern Ireland experience deprivation of liberty in a number of settings including residential institutions (for both adults and children), group homes, nursing homes, psychiatric hospitals and other settings. In addition, research demonstrates that a significant proportion of prisoners in Northern Ireland are disabled – with high levels of people with psychosocial disabilities incarcerated in the penal system.⁴³ For those who are deprived of their liberty in residential institutions, there are limited legal safeguards or opportunities for individuals to challenge the basis for their detention.

Human Rights Obligations

Article 14 CRPD provides that ‘in no case shall disability be a basis for

⁴³ Criminal Justice Inspectorate NI ‘Not a Marginal Issue Mental Health and the criminal justice system in Northern Ireland – A follow-up inspection’, (CJINI, March 2012). <http://www.cjini.org/getattachment/cdf1021e-d5e0-4cae-a11e-9ec36f988d4c/Not-a-Marginal-Issue--Mental-health-and-the-crimin.aspx> accessed 20 November 2020

detention'. According to the Guidelines on Article 14 produced by the CRPD Committee, this means that disability cannot be used as even part of the justification for deprivation of liberty. Therefore, laws that permit deprivation of liberty on the basis of disability in addition to other criteria such as dangerousness or risk of harm to self or others, are incompatible with the UN Convention and need to be repealed. The CRPD does not mean that d/Deaf and disabled people can never be deprived of their liberty, only that any deprivation of liberty which d/Deaf and disabled people experience, must be 'on an equal basis with others' and that deprivation of liberty must not be 'arbitrary' or 'unlawful.' The right to liberty is also protected in the European Convention on Human Rights and the International Covenant on Civil and Political Rights – and while there are some differences in approach to the right across these human rights instruments, the panel agree that the CRPD is the most up to date expression of how the right should apply to d/Deaf and disabled people.

Barriers

The Mental Capacity Act 2016 in Northern Ireland allows for people over the age of 16 to be deprived of their liberty where they are deemed to lack capacity 'because of an impairment of, or a disturbance in the functioning of, the mind or brain.' While emergency decisions about deprivation of liberty for a person who lacks capacity can be made by a person who reasonably believes the individual to lack capacity, long-term decisions about deprivation of liberty must be authorised by a panel appointed under the Act and are subject to review by a tribunal. The use of 'impairment or disturbance in the functioning of the mind or brain' as part of the definition of those who can be deprived of liberty under the Act arguably constitutes disability-based discrimination.

These approaches have been deemed by the CRPD Committee to be a violation of Articles 12 and 14 CRPD.⁴⁴ Further issues for human rights compliance include the fact that the 2016 Act's provisions on deprivation of liberty only apply to a place where 'care or treatment' is provided – and therefore might exclude environments such as private family homes where d/Deaf and disabled people may also be deprived of their liberty without access to legal remedies to challenge their situation. With respect to deprivation of liberty in the prison system, more efforts are also needed to improve accessibility and equality for d/Deaf and disabled prisoners. Previous research has demonstrated the need for more efforts to support prisoners in Northern Ireland at risk of suicide and self harm.⁴⁵ In keeping with the CRPD, any efforts to address this problem need to be human rights compliant, based on informed consent of the individuals, and not further the use of coercion and forced treatment in the prison environment or other forensic settings as this constitutes further human rights violations under Article 25 CRPD.

⁴⁴ UN Committee on the Rights of Persons with Disabilities, General Comment No. 2 (2014) Article 12: Legal Capacity (CRPD/C/GC/1)

⁴⁵ National Preventative Mechanism, 'Report on an announced inspection of Maghaberry Prison 19-23 March 2012' (NPM, 17 December 2012) <https://www.justiceinspectorates.gov.uk/prisons/wp-content/uploads/sites/4/2014/03/magahberry-2012.pdf> accessed 20 November 2020

Measures

Action
Reform the Mental Capacity Act 2016 to remove discrimination on the basis of disability in the context of deprivation of liberty
Provide access to supports for d/Deaf and disabled people who experience deprivations of liberty to ensure that they have real opportunities to legally challenge their situation, including legal aid
Extend application of Disability Discrimination Act 1995 to include prisoners
Work to bring an end to the use of coercive interventions in health and social care, including by funding and supporting alternative community-based non-coercive supports, including supports for people in crisis or distress, led and designed by d/Deaf and disabled people
Commission further research into experiences of disabled prisoners in Northern Ireland and commit to implement recommendations with particular emphasis on prisoners with experience of mental health services who self harm
Extend National Preventative Mechanism's work in NI into deprivation of liberty of d/Deaf and disabled people in residential and forensic settings

3.6 Freedom from Exploitation, Violence and Abuse

Issue

Deaf and disabled people in Northern Ireland are at higher risk of experiencing violence, exploitation and abuse compared to their non-disabled counterparts. The results of a Freedom of Information request made by Leonard Cheshire and United Response showed that disability hate crime incidents increased by 36% from 2018-2019 to 2019-2020.⁴⁶ This risk can be exacerbated by gender, and Women's Aid Northern Ireland reporting in 2018-2019 that 62% of women in domestic violence refuges and 34% of women accessing outreach services identified as having a disability or additional support needs.⁴⁷ The potential for exploitation, violence and abuse can be exacerbated in institutional settings, as the Public Investigation announced by Minister Swann into Muckamore Abbey Hospital in September 2020 demonstrates.⁴⁸

⁴⁶ Leonard Cheshire, 'Reports of violent disability hate crime continue to rise as number of police charges fall again' (Leonard Cheshire, 8 October 2020) <https://www.leonardcheshire.org/about-us/our-news/press-releases/reports-violent-disability-hate-crime-continue-rise-number-police> accessed 20 November 2020

⁴⁷ Women's Aid Federation Northern Ireland, 'Annual Report 2018-2019' (Women's Aid, January 2020) <http://www.womensaidni.org/assets/uploads/2020/01/A4-Womens-Aid-Annual-Report-2018-19.pdf> accessed 20 November 2020

⁴⁸ Department of Health, 'Muckamore patients and families invited to help shape Public Inquiry' (Department of Health, 20 November 2020) <https://www.health-ni.gov.uk/news/muckamore-patients-and-families-invited-help-shape-public-inquiry> accessed 21 November 2020

Human Rights Obligations

Article 16 CRPD provides that States take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects. This includes the need to provide protection, recovery and reintegration services for those who have experienced violence, exploitation and abuse “in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person.”⁴⁹ States cannot rely on their responsibility to protect d/Deaf and disabled people from abuse as a justification for further depriving them of their liberty, i.e. in institutional settings, or restricting their autonomy by imposing protection services without the individual’s consent. All measures taken to protect d/Deaf and disabled people from violence and to support them to recover from it must be based on the person’s consent, in the same way that non-disabled people’s consent would be required in order to provide support.

Barriers

There is no single source of evidence on violence, exploitation and abuse of d/Deaf and disabled people within care systems in Northern Ireland. The RQIA and the Health and Social Care Trusts along with PSNI all have responsibilities under the Adult Safeguarding Policy, but this policy has not been placed on a legislative footing. According to the Adult Safeguarding Policy, it is possible for protective interventions to be made for an adult at risk of harm in some cases without the individual’s consent.⁵⁰

⁴⁹ Article 16(4), CRPD

⁵⁰ Northern Ireland Adult Safeguarding Partnership, ‘What happens after you report a concern?’ (Health and Social Care Board, 2020) <http://www.hscboard.hscni.net/download/PUBLICATIONS/safeguard-vulnerable-adults/niasp-publications/niasp-what-happens-after-you-report-a-concern.pdf> accessed 20 November 2020

While available evidence shows that d/Deaf and disabled people are accessing mainstream supports including domestic violence refuges and outreach services, no information is available on the accessibility standards within those services for d/Deaf and disabled people, such as the availability of sign language interpretation, access for wheelchair users in refuges, etc. While some efforts have been made to improve access for d/Deaf and disabled people e.g. in online forms available to report hate crime to the PSNI, barriers remain for d/Deaf and disabled people, especially those in institutional settings, who do not have independent access to the internet or who require support in order to fill out a form.

There are also concerns that d/Deaf and disabled people may have been victims of human trafficking in Northern Ireland,⁵¹ but little support and information for victims of trafficking is available in accessible formats for d/Deaf and disabled people.

Measures

Action

Develop Adult Safeguarding legislation in collaboration with d/Deaf and disabled people and their representative organisations, ensuring that all interventions are based on informed consent

51 Bronagh Byrne, Barry Fitzpatrick, Colin M Harper, Hannah Russell, Rebecca Shea Irvine, 'Disability Programmes and Policies: How Does Northern Ireland Measure Up?' (Equality Commission for Northern Ireland, 2012), 147 <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/UNCRPDmonitoringimplementationFullReport0112.pdf?ext=.pdf> accessed 20 November 2020

Action

Increase accessibility for d/Deaf and disabled people in reporting an incident and throughout any resulting criminal process, including through provision of sign language interpreters, independent support to fill out forms, etc

Commission further research to understand experiences of d/Deaf and disabled people in accessing domestic violence services and supports and access legal redress

Increase funding and availability of independent advocacy to enable d/Deaf and disabled people to report abuse in institutional settings

4.0 Equality and Non-Discrimination

Issue

Weak, ineffective and piecemeal disability equality legislation is leaving d/Deaf and disabled people in Northern Ireland vulnerable to discrimination in virtually every aspect of their lives.

The environment currently facing d/Deaf and disabled people in NI is one where their rights are not adequately protected and one where they face substantial barriers to seeking any meaningful redress against disability discrimination when it does occur. As of the date of writing this report, the two substantive pieces of enacted disability equality legislation in NI remain the Disability Discrimination Act (1995) (DDA) as amended and the Special Educational Needs and Disability (NI) Order (2005) (SENDO).

The DDA's provisions provide varying degrees of legislative protection in respect of rights relating to: employment, accessing goods, facilities and services, and the management, buying or renting of property, education, and transport.⁵²

The DDA also includes a public sector “disability duty” known as the “disability duties” which places statutory obligations on public authorities in section 49A of the legislation to “promote positive attitudes towards disabled people” and “encourage their participation in public life.” Section 49B requires public authorities to develop “disability action plans” to demonstrate how they will fulfil their statutory obligations in this regard.

52 Equality Commission of Northern Ireland, ‘Disability Discrimination Law in Northern Ireland: A short guide’ (Equality Commission, 2011) <https://www.equalityni.org/ECNI/media/ECNI/Publications/Individuals/DisabilityDiscrimShortGuide2011.pdf> accessed 10 December 2020

See Section 49A and Section 49B of the DDA, as amended by Article 5 of the Disability Discrimination (Northern Ireland) Order 2006.

The Equality Commission of Northern Ireland is required to report a public authority to the Assembly in a range of circumstances including where an authority has failed to submit a disability action plan or revised plan within the required timescale. The Equality Commission has only ever used its reporting enforcement powers on one occasion (January 2009), and no remedial action was taken with any public authority for late submission of action plans. The Equality Commission has no legislative enforcement powers to challenge those public authorities that fail to meet the requirements of the form and content of action plans as prescribed in chapter 4 of the Equality Commission's guide to the "disability duties".

In the only independent evaluation of the effectiveness of the disability duties⁵³ the evaluators concluded that reporting mechanism to the Assembly has impacted on the ability to "effect meaningful action where a public authority has not taken steps to comply with its duties". The research concluded that public authorities should address the disability duties "with similar gravitas to other laws, proportionate to the size and remit of the public authority".⁵⁴

53 Rosemarie McIlwhan, Sheila Rogers and Simon Bridge, Evaluating the Effectiveness of the Disability Discrimination (NI) Order 2006: Research Report Findings (Equality Commission, November 2009) <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/EvaluatingDisabilitydutieResearchFindings2010.pdf> accessed 10 December 2020

54 Ibid, 182

Perhaps this was why the research highlighted a considerable degree of cynicism amongst focus group participants about whether the duties would achieve their purpose.⁵⁵

Furthermore chapter 3 of the Equality Commission's Guide to the "disability duties" clarifies that public authorities need only have "due regard" meaning they must only have to take into account their obligations under the duties, giving greater consideration to those functions and policies that have the most effect on disabled people.⁵⁶ English case law in this area suggests that the sole purpose of "due regard" in public sector duties is concerned with compliance to a process intended to deliver equality goals, but does not have to deliver real equality outcomes or results.⁵⁷

⁵⁵ Ibid, 11

⁵⁶ Equality Commission of Northern Ireland, Section 75 of the Northern Ireland Act 1998: Monitoring Guidance for Use by Public Authorities (Equality Commission, July 2007), 22 (paras 3.1-3.5) <https://www.equalityni.org/ECNI/media/ECNI/Publications/Employers%20and%20Service%20Providers/S75MonitoringGuidance2007.pdf> accessed 11 December 2020

⁵⁷ See R (Brown) v Secretary of State for Work & Pensions & the Secretary of State for Business, Enterprise and Regulatory Reform [2008] EWHC 3158 (Admin); R (Baker) v Secretary of State for Communities & Local Government and the London Borough of Bromley [2008] EWCA Civ 141; R. (on the application of Bracking) v Secretary of State for Work and Pensions [2013] EWCA Civ 1345

Section 75 of the Northern Ireland Act 1998 also requires public authorities to have “due regard” in consideration of their obligations to the need to promote equality of opportunity in relation to nine equality categories that includes d/Deaf and disabled people. The promotion of equality of opportunity entails the positive promotion of equality as well as the elimination of discrimination and is covered by anti-discrimination legislation. This duty should not deter a public authority from taking action to address disadvantage among particular sections of society that may be an appropriate response to addressing inequalities. The Equality Commission’s Guide on Section 75 makes clear that there is no conflict between the Section 75 statutory duties and other affirmative or positive action measures which a public authority may undertake under anti-discrimination laws including the DDA.

The formal effectiveness reviews of Section 75 accompanied by a substantive body of other research have highlighted conflicting views as to how successful this legislation has been in delivering equality of opportunity for d/Deaf and disabled people and the eight other equality categories covered under Section 75. The question of to what extent Section 75 goals actually influence policy formulation and practice in the delivery of equality of opportunity objectives by public authorities is the subject of endless debate. Of course the issue of “due regard” and its limitations is equally applicable when considering the future and purpose of Section 75. There is also the issue of how affordable and accessible the legal remedy of a judicial review is to enable d/Deaf and disabled people and others on low incomes to challenge any alleged failure of a public authority to take into account its equality obligations under Section 75 and whether or not the process is likely to deliver any real outcomes.

Legal challenges alleging breaches of the public sector equality duties, from our analysis of available case law available on the Equality Commission's website, appear to yield little in the way of positive tangible outcomes or results. Even successful challenges, including a disability related case which found the public authority in question was in breach of its duty under Section 75, did not result in the disabled person getting the equality consideration they sought.⁵⁸

Human Rights Obligations

The principle obligation in relation to ensuring appropriate disability equality legislation in Northern Ireland is found under Article 5 (2) of the CRPD:

'States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.'⁵⁹

Recent state examination of the UK Government by CRPD Committee in 2017 has specifically highlighted and been highly critical of the ongoing disparity in legal protections in Northern Ireland. In its concluding observations⁶⁰ the CRPD Committee specifically recommended bringing all

⁵⁸ Re Toner [2017] - Section 75 and developing a public realm scheme in Lisburn (Equality Commission, 2018) <https://www.equalityni.org/Employers-Service-Providers/Public-Authorities/Section75/Case-Law/Legal-Case-6> accessed 11 December 2020

⁵⁹ United Nations Convention on the Rights of Persons with Disabilities, Article 5(2)

⁶⁰ Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1, paras 17(a)-(b)

law into line with the convention and that the NI Executive adopt the legislative reform recommendations of ECNI which strengthen disability legislative laws than those contained in the Equality Act of 2010 and more in keeping with CRPD Article 5⁶¹.

Barriers

The Equality Commission for Northern Ireland (ECNI) has held responsibility since 1998 for reviewing disability discrimination law and overseeing and monitoring public sector disability duties. The Department for Communities (DfC) currently holds responsibility for drafting new and upgrading existing disability equality law.

The key barrier to effective legislative protection for d/Deaf and disabled people in NI is an ongoing failure to prioritise, draft and bring new domestic legislation before the Executive. This failure continues in spite of the CRPD placing a clear obligation on states to ensure realisation/ protection of rights within domestic legislation. The provisions of the Equality Act 2010 replaced the DDA in Great Britain, bringing additional protections to the rest of the UK. At that point in time there was an opportunity for harmonisation of protections in NI, however this opportunity was missed. The most pressing areas in need of urgent reform, namely the gaps in protection between DDA and the Equality Act as outlined by the ECNI since 2009 onward⁶² remain unfulfilled:

⁶¹ Equality Commission, 'Strengthening Protection for Disabled People Proposals for Reform' (ECNI, 2012) https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/Strengthening_protection_for_disabled_people0312.pdf accessed 20 November 2020

⁶² Ibid 3

1. Disability legislation is harmonised, simplified and strengthened, so that there is a uniform set of definitions of discrimination and other provisions across the scope of the legislation.
2. Deaf and disabled people have protection against indirect disability discrimination and discrimination arising from disability; thus addressing the impact of the House of Lords' decision in June 2008 in the case of *Mayor and Burgesses of the London Borough of Lewisham v Malcolm* (Malcolm).
3. The definition of disability is amended so as to remove the list of capacities from the definition; thereby making it easier for d/Deaf and disabled people to fall within the definition of disability.
4. There is express protection for people, such as carers, friends or family members, who are subjected to direct discrimination or harassment because of their association with a disabled person, or because they are wrongly perceived to be disabled.
5. There is increased protection for d/Deaf and disabled people from harassment related to their disability when accessing goods and services, or private clubs.
6. Questions by employers related to disability and health before a job offer is made are prohibited, except in specified circumstances.
7. There is an additional duty on schools to provide auxiliary aids and services for disabled pupils, where reasonable.
8. Disabled tenants who live in rented residential accommodation are given additional protection in relation to the making of reasonable adjustments by landlords to common parts (such as an entrance hall in a block of flats).

The weaknesses of the DDA, and public sector ‘due regard’ duties have gone unaddressed for too long, creating an extremely challenging and hostile environment for d/Deaf and disabled people. These challenges have only been exacerbated by both political austerity⁶³ and the ongoing global pandemic.⁶⁴ It is very important to note; more than a decade on these reform recommendations remain urgent minimums. Mere harmonisation with Equality Act Provisions at this point would be too little, much too late.

However the Equality Act 2010 could act as a basis (a starting point) for reform of both the public sector equality duties here, covered by both the DDA and S75:

In summary, public authorities subject to the general equality duty must also have due regard to the need to eliminate unlawful discrimination, harassment and victimisation. The duty to have due regard to the need to eliminate discrimination in the area of employment also covers marriage and civil partnerships. The equality duty also requires public authorities to collect data including:

63 Committee on the Rights of Persons with Disabilities (2017) Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention. CRPD/C/15/4 <https://www.equalityni.org/ECNI/media/ECNI/Publications/Corporate/IMNI%20meetings/2017/CRPD17-1-6Jan17OverviewCRPDInquiry.pdf> accessed 20 November 2020

64 Alison Crawford, Sean Fitzsimmons and Emma O'Neill (2020) The Impact of Covid-19 on Disabled People in Northern Ireland, Disability Action Available at: <https://www.disabilityaction.org/Handlers/Download.ashx?IDMF=fdb4ec49-e3b3-472c-b31a-57d87523b71a>

- gather and use employee information
- publish information on board diversity and succession planning
- publish disability pay gap information
- publish gender pay gap information
- publish statements on equal pay
- consider award criteria and conditions in relation to public procurement
- publish required information in a manner that is accessible
- collecting information on gender identity

Measures

Action
Urgent prioritisation given by the Minister for Communities and her Department to drafting new Disability Equality Legislation which fully incorporates the CRPD into domestic legislation
Accept and act on the proposals of the Equality Commission for Northern Ireland to reform disability equality legislation to address gaps in legal protections for d/Deaf and disabled people living in Northern Ireland which better reflect CRPD rights than the Equality Act 2010 as recommended by the CRPD Committee
Consider new legislation to strengthen the compliance and enforcement framework associated with the “due regard” public sector equality duties, within the DDA and Section 75 including consideration of the betterment substitution of the “due regard provisions.”

Action

Consider the additional obligations on public authorities in the Equality Act 2010 as a starting point for strengthening the public sector equality duties in DDA and Section 75, taking account of earlier recommendations prioritising those of greater benefit

Support the Equality Commission to work with the Executive Office and Northern Ireland Assembly to introduce effective enforcement powers relating to the obligations of public authorities who fail to meet the requirements of the disability duties either in terms of form and content of disability action plans

Adequately resource the Equality Commission to deliver effectively its existing and any new enforcement powers relating to the recommendations above

Any new Bill of Rights for Northern Ireland (especially in light of the fact that the Human Rights Act may be repealed) should specifically recognise disability based discrimination

Post-Brexit, maintain pace in NI law with developments in EU legislation relating to disability discrimination and equality (including for example the EU Accessibility Act)

Introduce new legislation to give effect to a comprehensive legal aid scheme to ensure d/Deaf and disabled people can access their rights under the DDA and the equality of opportunity duty under Section 75

5.0 Accessibility

5.1 General Accessibility

Issue

Accessibility is fundamental to d/Deaf and disabled people's inclusion and independence. Issues relating to accessibility are set out in some detail across this report, with access duties examined under equality and non-discrimination above. However, it is also critical that the concept and scope of accessibility is considered in its own right.

Accessibility can be understood as a pre-condition for d/Deaf and disabled people to live independently and to participate fully and equally in society in a meaningful way.⁶⁵ Without access to the physical environment, to transportation, to information and communication, and to other facilities and services open or provided to the public, d/Deaf and disabled people would not have equal opportunities for participation. This is reaffirmed by the fact that 'accessibility' is a key general principle set out in Article 3 of the CRPD.

Human Rights Obligations

In addition to the establishment of accessibility as a general principle, Article 9 of the CRPD stipulates that, "to enable persons with disabilities to live independently and participate fully in all aspects of life, States parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communication, including information

⁶⁵Committee on the Rights of Persons with Disabilities (2014) General Comment No.2: Accessibility. UN: CRPD/C/GC/2, para 1

and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas”.

Article 9(2) requires states to identify and eliminate obstacles and barriers to accessibility to, (a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces; and (b) Information, communications and other services, including electronic services and emergency services. The CRPD Committee has clarified that the ‘other indoor and outdoor facilities’ should include law enforcement agencies, tribunals, prisons, social institutions, areas for social interaction and recreation, cultural, religious, political and sports activities, and shopping establishments, and that other services should include postal, banking, telecommunication and information services.

Finally, Article 9(3) stipulates the measures States parties must take in order to develop and monitor the implementation of minimum national standards for the accessibility of facilities and services open or provided to the public.

In its General Comment on accessibility⁶⁶, the CRPD Committee has specified that denial of access should be considered to constitute a discriminatory act, regardless of whether the perpetrator is a public or private entity. Further, that the right to access is to be ensured through strict implementation of accessibility standards. It has also emphasised strict application of universal design to all new goods, products, facilities,

66 Committee on the Rights of Persons with Disabilities (2014) General Comment No.2: Accessibility. UN: CRPD/C/GC/2, para 13

technologies.⁶⁷ For example, d/Deaf and disabled people should be able to move in barrier-free streets, enter accessible low-floor vehicles, access information and communication, and enter and move inside universally designed buildings, using technical aids and live assistance where necessary.

Barriers

In its 2017 examination of the UK, the CRPD Committee expressed concern at the insufficient scope, content and number of obligatory and implemented accessible standards relating to, among others, the physical environment, affordable housing, ICT, and information in urban and rural areas. It was also concerned that austerity measures have hindered the advancement of accessibility.⁶⁸

⁶⁷ Committee on the Rights of Persons with Disabilities (2014) General Comment No.2: Accessibility. UN: CRPD/C/GC/2, para 17

⁶⁸ Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1, para 24-25

There have been references to the need for increased accessibility across some previous strategies but no further details on how this would be achieved in practice. The IMNI Jurisdictional Parallel report presented to the CRPD Committee in 2017 highlights a range of physical barriers that d/Deaf and disabled people in Northern Ireland experience.⁶⁹

Measures

Action

Commit to a full review in meaningful partnership with d/Deaf and disabled people and their organisations of all statutory controls that influence the built environment including the public realm and the natural environment and make the necessary amendments to ensure compliance with the CRPD. This review should include both existing and any new developments

Promote digital inclusion and access to communication and information technologies for d/Deaf and disabled people of all ages and ensure that these are accessible at minimum cost

Ensure that departmental information and communications are available in easy-to-read formats and alternative accessible methods for d/Deaf and disabled people who require it

69 IMNI (2017) Northern Ireland Parallel Jurisdictional Report to CRPD Committee [https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI_CRPD_ParallelJurisdictionalReport_WorkingPaper\(Aug17\).pdf](https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI_CRPD_ParallelJurisdictionalReport_WorkingPaper(Aug17).pdf) Adapt NI with BMKent Consulting (April 2013): ‘ABC audit benchmark change – State of disability access report 2013’, page 10 (Belfast: Equality Commission NI). Available at: <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/Audit-Benchmark-Final-Reportsubmit20June13.pdf>

Action

Develop clear accessibility standards in consultation with d/Deaf and disabled people and their representative organisations, taking into account the diversity of d/Deaf and disabled people and ensure that accessibility is provided to persons of any gender and of all ages and types of disability

Changing Places should be a mandatory requirement in all public spaces. These should be provided in addition to, and not instead of, standards accessible toilets

Adopt inclusive design standards (BS8300) in its procurement policies

5.2 Transport

Issue

Access to transport is a long-standing issue which can have a direct impact on the ability of d/Deaf and disabled people to exercise their rights to, for example, independent living, education, employment, health, and access to culture, arts and leisure. The physical inaccessibility of public transport has been recognised by the CRPD Committee as a major factor in the ongoing marginalisation and exclusion of both disabled children and adults. In addition, people with learning disabilities, hidden disabilities, mental health disabilities as well as autistic, d/Deaf, visually impaired and deaf-blind people can face barriers when attempting to access information about transport and communication on transport facilities due to a lack of easy-to-read formats and augmentative and alternative modes of communication. They can also face barriers when attempting to access services due to prejudices and a lack of adequate training of the staff providing those services.

Human Rights Obligation

Article 9 of the CRPD makes it clear that access to transport is critical if persons with disabilities are to live independently and participate fully in all aspects of life. This right extends to both in urban and in rural areas. It requires states to take measures including the identification and elimination of obstacles and barriers to accessing transport.

Barriers

Research conducted by the Inclusive Mobility Transport Advisory Committee (IMTAC) and by the Equality Commission for Northern Ireland has found that d/Deaf and disabled people experience a range of barriers to accessing transport. This includes inaccessibility of facilities as well as poor service.⁷⁰ Existing evidence suggests that d/Deaf and disabled people are 7 times more likely to have difficulty getting on and off vehicles than non-disabled

70 Inclusive Mobility Transport Advisory Committee (2009): ‘Improving the provision of Disability Equality and disability awareness training – Good practice guidelines for transport providers’. Available at: <https://www.imtac.org.uk/publications/improving-provision-disability-equality-and-disability-awareness-training-good-practice> Bronagh Byrne, Barry Fitzpatrick, Colin M Harper, Hannah Russell, Rebecca Shea Irvine, ‘Disability Programmes and Policies: How Does Northern Ireland Measure Up?’(Equality Commission for Northern Ireland, 2012), 106 <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/UNCRPDmonitoringimplementationFullReport0112.pdf?ext=.pdf> accessed 20 November 2020. page 106

people, 3 times more likely to have difficulty getting to public transport and twice as likely to have difficulty accessing information about transport.⁷¹ Other barriers include unaccommodating hours of the door-to door transport service, the lack of physical access to public transport, prohibitive costs of private transport (particularly taxis and mini buses) and the lack of understanding and awareness of disability by some transport companies.⁷² These challenges have been compounded by cuts in funding and/or services through austerity.

While there have been improvements to public transport, many of the improvements have benefitted people travelling in the Greater Belfast area the most, with travel by public transport more challenging for people living in other areas. The disparity in the accessibility between services in Greater Belfast and other areas is a major barrier to travel for d/Deaf and disabled

71 Department for Regional Development (2015): ‘Attitudes of Disabled and Older People towards Public Transport November 2014 – January 2015’, Table 3, page 40. Available at: <https://www.gov.uk/government/statistics/attitudes-of-older-and-disabled-people-to-public-transport-nov-14-to-jan-15> IMTAC (May 2015): ‘Comments on the DRD report of the results from the Attitudes of Disabled and Older People to Public Transport Survey’. Available at: <https://www.imtac.org.uk/publications/comments-drd-report-results-attitudes-disabled-and-older-people-public-transport-survey>

72 Equality Commission for Northern Ireland (2017) United Nations Convention on the Rights of Persons with Disabilities Jurisdictional ‘Parallel’ Report on Implementation in Northern Ireland: Working Paper. ECNI: Belfast

people in Northern Ireland.⁷³ Deaf and disabled people who rely on alternative transport services such as taxis and rural and urban community transport services, have reported that access to these services is becoming increasingly challenging.⁷⁴

Inaccessibility in the pedestrian environment can further restrict access to local services, facilities and wider travel. This can include overuse of street furniture such as A boards and parking on pavements. Street furniture has become even more of an issue in the current pandemic period as cafes and restaurants move to outside spaces. The extent to which d/Deaf and disabled people and their families are able to travel can also be impacted by the availability of accessible toilet facilities and Changing Places facilities; something which should not be a consideration in the 21st century.

In its 2017 Concluding Observations to the UK, the CRPD Committee expressed concern at the insufficient scope, content and number of implemented accessible standards relating to transport, among other areas.⁷⁵ The Committee called on the UK to identify outstanding gaps in terms of accessibility standards in all areas of the Convention, among others, the design of affordable and accessible physical environments, information formats and transport infrastructure, including emergency services and green and public spaces in both urban and rural areas, and

73 IMTAC (2019) Annual Report 2018/19. Available at <https://www.imtac.org.uk/publications/imtac-annual-report-2019>

74 Ibid

75 Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1, para 24

ensuring that standards are met. The Committee has also emphasised the importance of transport in the development of community-based independent living schemes.⁷⁶

Measures

Action
Work with IMTAC and others on the following eleven recommendations:
Vehicle design for public transport to offer consistent level of access across urban and rural areas
Extend the provision of audio visual next stop information systems on all public transport
Remove notice requirements for wheelchair users to travel on Translink services
Increase investment in accessible transport modes and services including transport infrastructure
Review the bus/train concessionary smart pass to allow for free travel for all d/Deaf and disabled people in receipt of the mobility component of PIP or DLA
Allow for the use of concessionary passes to be extended to return journeys
Allow online bookings for those with concessionary passes

⁷⁶ Committee on the Rights of Persons with Disabilities (2017) Concluding Observations on the Initial Report of the United Kingdom of Great Britain and Northern Ireland. UN: CRPD/C/GBR/CO/1, para 25

Action

Ensure all those working in transport services receive d/Deaf and disability equality training

Implement a pavement café licensing system that prioritises pedestrians

Explore the introduction of a ban on A Boards on pavements

Explore options for preventing parking on pavements

5.3 Employment

Issue

Deaf and disabled people in Northern Ireland are at a substantial disadvantage to their non-disabled peers in gaining, retaining and progressing in employment. As with most other areas of their lives, a complex myriad of socially and systemically created barriers create an almost perfect storm, affecting employment chances and career development⁷⁷. The economic benefits derived from meaningful employment are intrinsically linked to the full and effective realisation of other rights and freedoms. Employment is a major contributing factor in the fundamentals of independence, health and participation.

⁷⁷ 'Ahead of the Arc' – A contribution to halving the disability employment gap. (2016) Available at:

<https://www.disabilityrightsuk.org/sites/default/files/pdf/AheadoftheArc110518.pdf>

Statistics for Northern Ireland are sobering, year on year they demonstrate the sheer impact of barriers faced, with the most recent Labour Force Survey figures showing only 38.9% of working age d/Deaf and disabled people in NI being in employment, this is in contrast to their non-disabled peers who in the first quarter of 2020 had an employment rate of over 80.1%. This means at last analysis NI's disability employment gap sits at 41.2%.⁷⁸

It's important to note that Great Britain's comparatively 'better' figures of 53.1% of working aged d/Deaf and disabled people in employment, and a smaller disability employment gap of 28.6% have triggered such concern as to recently have a Work and Pensions Committee announce an inquiry into how the Department for Work and Pensions can better support d/Deaf and disabled people there⁷⁹. At an EU level the current average of working aged d/Deaf and disabled people in employment sits at 50.8%, with EU targets as of 2020 aiming to raise this figure to 75%⁸⁰. Within the UK context alone, Northern Ireland is and remains the most challenging place to be if you are seeking to gain, retain or progress in employment as a disabled person.

78 NISRA - Quarterly Labour Force Survey Tables, Disability and the labour Market (August 2020) Available at:

<https://www.nisra.gov.uk/publications/quarterly-labour-force-survey-tables-august-2020>

79 Department for Work & Pensions, Disability Employment Gap Inquiry (November 2020) Available at: <https://committees.parliament.uk/work/751/disability-employment-gap/>

80 Poverty and Social Exclusion of Persons with Disabilities – European Human Rights Report Issue 4 (2020) Available at: <http://www.edf-feph.org/employment>

Human Rights Obligations

Domestically in NI the principle protections for d/Deaf and disabled people in employment are found within the Disability Discrimination Act 1995 (DDA) as amended. There are however significant and well documented weaknesses in this legislation⁸¹. These weaknesses coupled with the failure to achieve legislative parity in 2010, mean protections which exist elsewhere in the UK for disabled people (and their family members) do not exist in NI. This ongoing legislative failure is foundational in both enabling and entrenching systemic inequality and discrimination in employment.

The principle international obligation in relation to protecting the right to work and employment for d/Deaf and disabled people is found under Article 27(1) CRPD:

‘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...’⁸²

81 Strengthening protection for disabled people: Proposals for law reform - summary report, ECNI, (2012) Available at: <https://www.equalityni.org/ECNI/media/ECNI/Publications/>

82 United Nations Convention on the Rights of Persons with Disabilities Article 27 Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-27-work-and-employment.html>

Barriers

It is important to note, there are some positive examples of Government employment support programmes for d/Deaf and disabled people⁸³, as well as other programmes such as European Social Fund Programme (ESF) administered by the Department for the Economy and matched funded by various departments such as the Department for Communities and the Department of Health; this programme is the main pre-employment and training programme provided by Government.

There have also been notable progressive attempts at breaking new ground in respect of previous disability employment strategies⁸⁴.

Despite these, however, d/Deaf and disabled people continue to remain hugely disadvantaged. Their voices (when listened to) speak of ongoing stress and anxiety in relation to overcoming the most basic of disability related barriers in employment.⁸⁵ Furthermore, those d/Deaf and disabled people furthest from the labour market such as those with high complex support requirements face even greater disadvantage in accessing, retaining and progressing in employment.

83 Workable NI, Access to Work & Condition Management Programme

84 Supporting Equality Through Inclusive Employment' An Employment Strategy for People with Disabilities, DELNI, 2016 Available at: <https://www.communities-ni.gov.uk/sites/default/files/consultations/del/Disability%20Strategy%20report%20%28Web%29.pdf>

85 Hard at Work: Employment and Disability in Northern Ireland, Disability Action (2015)

Whilst available quantitative data on disability employment in NI gives a critical macro level overview, it fails to give voice to the complexities of individual lived experience and impairment. It is acknowledged that disability specific, appropriately designed and delivered macro level interventions will be the only way to positively ‘shift the dial’ on disability employment.

There has historically been much consultation, but limited or no meaningful co-design/ production of employment services aimed at supporting d/Deaf and disabled people. This is true of both NI specific programmes and UK wide counterparts which transfer across from Department for Work and Pensions (DWP). This has at best led to some programmes not supporting equally the intricacies of differing individual impairment barriers and indeed being referred to ‘Government’s best kept secret’⁸⁶ At worst it has led to programmes/interventions being deployed which have included mandating disabled participants through social security conditionality. The ineffectiveness and damage of the latter ‘stick and stick’ approach has long been voiced by d/Deaf and disabled people and thoroughly discredited through academic rigour.⁸⁷

86 Getting In, Staying In and Getting On – Disability Employment Support Fit for the Future, Sayce L, (2011) Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/49779/sayce-report.pdf

87 Welfare Conditionality Project 2013-2018, (2018) Available at: http://www.welfareconditionality.ac.uk/wp-content/uploads/2018/06/40475_Welfare-Conditionality_Report_complete-v3.pdf

The scope of the DDA falls well short of providing an acceptable standard of protection within employment for d/Deaf and disabled people in NI. More than a decade of divergence in jurisprudence arising has caused considerable difficulty to d/Deaf and disabled people facing various forms of discrimination when attempting to gain, retain and progress in employment.

More than a decade of political austerity has only added fuel⁸⁸ to an already unrelenting toxic narrative in respect of d/Deaf and disabled people and their place in and value to wider society⁸⁹. This backdrop has exacerbated already existent challenges by adding to deeply entrenched stereotypes of d/Deaf and disabled people being fraudulent, a burden, inefficient or costly. These persistent negative tropes trickle relentlessly into workplaces, affecting organisational policy, practice and culture.

Measures

Action
Develop a new Disability Employment Strategy in meaningful partnership with d/Deaf and disabled people and relevant statutory and voluntary organisations
Ensure that disability employment law is revised to reflect provisions within the Equality Act 2010 to ensure at least parity of treatment of all d/Deaf and disabled people across the UK
Develop disaggregated and qualitative data to better inform employment policy, shape programme design/delivery and ensure better outcomes

88 The War on Disabled People: Capitalism, Welfare and the Making of a Human Catastrophe, Clifford. E, 2020

89 Katherine Quarmby ‘Scapegoat : Why We Are Failing Disabled People’ (London, 2011)

Action

Ensure that currently proposed and future training and employment programmes (current programmes include ESF) are clearly linked across Departments. That by default they are co-produced with d/Deaf and disabled people, specialised and not a 'one size fits all' provision

Prioritise d/Deaf and disabled people within social clauses linked to employment practice within all Government procurement contracts

NICS need to realign representation to at least match the percentage of d/Deaf and disabled people in employment in GB Civil Service. Firmly commit to development and roll out positive action (i.e. ring fencing posts) employment measures aimed at securing, retaining and progressing d/Deaf and disabled people through all levels of the NICS

Monitor and address the disability pay gap in employment

Incorporate access to work as a potential mechanism to support d/Deaf and disabled people in work experience to access employment in the first place – particularly in accessing equipment, transport, work-related expenses and personal assistance

Immediately work towards ending the practice of sheltered employment and other poor practices and advance creative opportunities for d/Deaf and disabled people to access meaningful jobs in a wide range of sectors

End the practice of reasonable adjustment being used as a punitive or restrictive measure on d/Deaf and disabled people and ensure that reasonable adjustments continue to be respected when the employer's situation or external circumstances have changed (e.g. in light of Covid 19)

Work with those responsible for the Disability Employment Stakeholder Forum on the following three recommendations:

Action

Funding for Supported Employment model for d/Deaf and disabled people furthest from the labour market

Develop a broad range of options to ensure d/Deaf and disabled people can participate at all levels in the labour market (recruitment, retention and promotion/advancement)

Access to work to support d/Deaf and disabled people in training and work experience and greater public awareness programme

5.4 Education

Issue

Data indicates that there are 67,000 pupils in schools who have some form of SEN; this is 19.3% of the school population⁹⁰. Of this, 19,000, or 5% of pupils, have a statement of SEN. Over 6,000 pupils are enrolled in 39 special schools. In addition to this, more than 2,000 are educated in learning support centres in primary and post-primary schools. The overall number of children with SEN in Northern Ireland has risen by 48% since 2004/05, and over the same period the number of children with statements has risen by

⁹⁰ <https://www.education-ni.gov.uk/sites/default/files/publications/education/revised%203rd%20March%202020%20-%20Annual%20enrolments%20at%20schools%20and%20in%20pre-school%20....pdf>

60%⁹¹. From 2008 to 2018 the number of pupils enrolled in special schools in Northern Ireland has also risen by 30%. Legislation for children with special educational needs (SEN) in Northern Ireland is contained within the Education (Northern Ireland) Order 1996 and the Special Educational Needs and Disability (Northern Ireland) Order 2005 and is supported by Codes of Practice and statutory regulations. The Executive's New Deal, New Approach 2020 states that "it will deliver a new Special Educational Needs Framework to support young people with special needs to achieve their full potential." A consultation on new draft SEN regulations and Code of Practice based on the Special Educational Needs and Disability (Northern Ireland) Act 2016 is currently underway at the time of writing.

Human Rights Obligations

Article 24 CRPD requires States Parties to ensure an 'inclusive education system at all levels'. States are obliged to ensure that d/Deaf and disabled people are not excluded from the general education system on the basis of disability, that they are able to access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live, and that they are provided with support to facilitate their effective education.

91 Noel Purdy, Gillian Beck, Diane McClelland, Celia O'Hagan, Lois Totton & Jonathan Harris 'Too Little, Too Late, The views of parents/carers on their child's experiences of the Special Educational needs (SEN) process in mainstream schools.' (NICCY, 2019) available at <https://www.niccy.org/media/3525/niccy-too-little-too-late-parents-report-2019-web-version.pdf> 10 December 2020

The rest of Article 24 sets out entitlements in relation to the use of alternative means of learning and formats of communication including the use of Braille, sign language and promotion of the linguistic identity of the d/Deaf community through education.

The meaning of Article 24 has been elaborated upon in General Comment 4. The document is significant for the clear message it conveys on the scope and content of 'inclusive education' and educational placement. The General Comment takes, as its starting point, the view that inclusion involves

'a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and the environment that best corresponds to their requirements and preferences. Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organisation, curriculum and teaching and learning strategies, does not constitute inclusion.'⁹² (UN 2016, 3)

Barriers

Despite improvements in the proportions of school leavers with any SEN or a disability achieving 5+ GCSEs (A*-C) and 5+ GCSEs (A*-C) including Maths and English, there continues to be an educational attainment gap between children with and without special educational needs. The attainment gap between SEN 1-4 pupils and those with no SEN decreased from 46 percentage points to 23 percentage points for those obtaining 5+ GCSEs Grades A*-C between 2007/08 and 2014/15. While pupils with SEN 5 have

⁹² Committee on the Rights of Persons with Disabilities (2016) General Comment No.4: The right to inclusive education. (UN, CRPD/C/GC/4) para 11

also experienced an increase in attainment, it has not been to the same extent as pupils with SEN 1-4; the attainment gap between SEN 5 pupils and those with no SEN decreased from 59 percentage points to 48 percentage points for those obtaining 5+ GCSEs Grades A*-C between 2007/08 and 2014/15.⁹³

There has been a raft of reports and reviews in recent years highlighting the shortcomings of the existing educational system for children with disabilities and who may have special educational needs. Most recently these include NICCY's (2019) 'Too Little, Too Late' report which uncovered a series of significant flaws in the system which have presented barriers for children and young people in accessing vital supports and services. It revealed a system under extreme pressure, unable to respond to the scale of need and the complexity of issues that children are presenting. In September 2020, the NIAO published a report on the impact of SEN, concluding that there was an absence of strategic evaluation of the support provided to these children to ensure the best possible outcomes. The report also highlighted inconsistencies in the identification of children with SEN and unacceptable delays in the statementing process. Also of ongoing concern is the lack of a clear pathway for young d/Deaf and disabled people who are transitioning from school to adult services, further education and employment.⁹⁴

93 ECNI (2017) Educational Inequalities in Northern Ireland. <https://www.equalityni.org/KeyInequalities-Education> 10 December 2020

94 Education and Library Boards (2012) Audit of Inequalities, Second Edition, 'Work in Progress' 180 Education and Training Inspectorate (2014) A Survey Report on Transition Arrangements from Special Schools and Mainstream Learning Support Centres to Post-School Provision; Lundy, Byrne and McKeown (2012) Scoping Paper on Transitions to Adult Services for Young People with Learning Disabilities, Belfast: NICCY; Byrne B. and McAlister, S. (2014) Transitions for Young People with Hearing Loss. Belfast: Action on Hearing Loss

There are ongoing significant concerns about increasing enquiries relating to disability discrimination in education; increasing numbers of cases where children are not attending school or are attending part-time due to informal exclusion. For example, the Children's Law Centre has noted that it is regularly contacted by parents of young children with special educational needs and/or disabilities who are sent home early from school; are educated part-time over a lengthy duration, or who have no suitable school placement to attend. These issues are exacerbated since informal exclusions are not formally documented or reported upon, resulting in a lack of data being available.⁹⁵ In its 2016 examination of the UK, the CRC Committee⁹⁶ highlighted that children with disabilities and special educational needs, are often subject to the practice of 'informal' exclusion or 'taught off-site' to control their behaviour; and that isolation rooms are used for disciplining children. The Committee called on the UK to abolish the use of isolation rooms and to use permanent or temporary exclusion as a means of last resort only, and to forbid and abolish the practice of 'informal' exclusions.

In its 2017 examination of the UK, the CRPD Committee expressed concern at the existence of a 'dual education system' that segregates children with disabilities in special schools; the increasing number of children with disabilities in segregated education environments; the fact that the education system is not equipped to respond to the requirements for high-quality inclusive education, particularly reports of school authorities refusing to enrol

95 Children's Law Centre (2020) Response to call for evidence on educational underachievement linked to socio-economic disadvantage

96 Committee on the Rights of the Child (2016) Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland. CRC/C/GBR/5, at para 73

a student with disabilities who is deemed to be “disruptive to other classmates”; and the fact that the education and training of teachers in inclusion competences does not reflect the requirements of inclusive education.

Measures

Action
Establish independent review on informal exclusions from school in Northern Ireland
Establish independent review on the extent to which restraint and seclusion is taking place, and ensure current guidelines are in line with rights-based standards
Implement NICCY and NIAO report recommendations
Ensure voices of children and their families are sought and heard in development and implementation of new SEN regulations and Code of Practice
Ensure a clear, joined up transitions pathway for all young d/Deaf and disabled people from school with appropriate support for young people and their families/carers
Collect consistent good quality data on educational outcomes, transitions and quality of educational experiences for d/Deaf and disabled children
Ensure mandatory training on disability and SEN across teacher training programmes
Explore how linguistic identity of the d/Deaf community can be best promoted throughout the education system

Action

Provision of GCSE sign language

5.5 Health

Issue

The right to the highest attainable standard of physical and mental health is a key concern for d/Deaf and disabled people in Northern Ireland. Significant work is needed to ensure that health services provided to the general public are accessible and responsive to the needs of d/Deaf and disabled people, and this is particularly critical at present given the disproportionate impact which the COVID 19 pandemic is having on the health of d/Deaf and disabled people in Northern Ireland. A critical issue also for d/Deaf and disabled people is the need to ensure that health treatment is provided based on the informed consent of the person concerned. The provision of healthcare based on proxy consent of next of kin or of staff in disability service providers is not appropriate and does not comply with Northern Ireland's human rights obligations under the CRPD.

Human Rights Obligations

According to Article 25 of the CRPD, States Parties have an obligation in making health services available to d/Deaf and disabled people, to ensure that services are provided as close as possible to people's own communities, including in rural areas. Health professionals are also obligated to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent, and States must prohibit the discriminatory denial of health care or health services on the basis of disability.

The CRPD Committee's Concluding Observations on the UK, issued in 2017, noted in particular the need for the State to develop a targeted, measurable and financed plan of action on access to health care and services, and monitor and measure its progress, especially in relation to persons with intellectual and/or psychosocial disabilities and those with neurological and cognitive conditions. The Committee found that d/Deaf and disabled people were not securing equal access to sexual and reproductive health-care services, and requested the state to provide information and education on family planning in accessible formats, including Easy Read. Finally, with respect to Northern Ireland in particular, the Committee noted the need to take steps to address the high suicide rate among persons with disabilities, especially persons with intellectual and/or psychosocial disabilities.

Barriers

Existing research has demonstrated the barriers faced by d/Deaf, hard of hearing, blind or partially sighted people in accessing primary health care in Northern Ireland, including the fact that less than half (47%) of the GP practices surveyed had made 'reasonable adjustments' specifically for people with a sensory disability, despite the provisions of the Disability Discrimination Act.⁹⁷ Mencap has also highlighted specific barriers in accessing healthcare faced by people with learning disabilities in Northern Ireland, including a lack of accessible information, insufficient support for the person to make a decision, a lack of staff training or understanding of learning disability, failure to recognise that a person with a learning disability is ill or in pain, for example, by focusing on their disability

97 RNID/RNIB/BMA, 'Is it my Turn Yet? Access to GP practices in Northern Ireland for people who are deaf, hard of hearing, blind or partially sighted within Northern Ireland' (RNID: 2010)

(diagnostic overshadowing).⁹⁸ In Disability Action’s Shadow Report to the CRPD Committee, it raised concerns about ‘Do Not Resuscitate’ orders “being placed in the hospital notes of people with learning disabilities, without their knowledge or consent.”⁹⁹ The CRPD Committee also made specific reference to the need to abolish this practice in its Concluding Observations to the UK.¹⁰⁰ Research conducted by Disability Action on the impact of COVID 19 on d/Deaf and disabled people in Northern Ireland also found that many respondents indicated a high level of worry and anxiety that they, or someone they care for, would not be able to access treatment for existing medical needs, and/or would be denied medical intervention if they contracted COVID 19.¹⁰¹

A lack of uptake in health screening services among d/Deaf and disabled people is also a barrier – and Mencap has noted that a lack of uptake in cervical cancer screening for people with learning disabilities is particularly problematic partly due to false assumptions that people with a learning

98 Department of Health and Social Care, “‘Right to be Heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff’ (Department of Health and Social Care, 5 November 2019

99 Disability Action, *Alternative Report on the Implementation of CRPD in Northern Ireland* (Belfast, 2017), at p.36

100 UN Committee on the Rights of Persons with Disabilities, *Concluding Observations on the First Periodic Report of the United Kingdom of Great Britain and Northern Ireland 2017* (CRPD/C/GBR/CO/1), para. 55(d)

101 Disability Action, *The impact of COVID-19 on disabled people in Northern Ireland* (Belfast, 2020).

disability are not sexually active and so do not need to be screened.¹⁰² Further, while mandatory learning disability training for health and social care professionals has been introduced in England, this has not been extended to Northern Ireland.¹⁰³ Concerns about the high suicide rate in Northern Ireland, especially when compared to other jurisdictions in the UK, have also been raised, along with a lack of access to non-coercive mental health treatment, and to supports for people experiencing emotional distress or mental health crises in the community.

Measures

Action
Involve d/Deaf and disabled people's organisations and individuals in the Developing Better Services programme which is designed to introduce more patient-centred approaches in Northern Ireland
Reform Health Service Ethical Advice and Support Framework and Clinical Ethics Forum to include meaningful representation and participation of d/Deaf and disabled people's organisations, especially measures to tackle diagnostic overshadowing

¹⁰² See Dimensions Responds to the LeDeR report 2019' (Dimensions, 22 May 2019) <https://dimensions-uk.org/press-release/dimensions-responds-leder-report-2019/> accessed 20 November 2020

¹⁰³ See Mencap, Treat Me Well (London: 2020) <https://www.mencap.org.uk/sites/default/files/2018-07/2017.005.01%20Campaign%20report%20digital.pdf> accessed 9 December 2020

Action

Include d/Deaf and disabled people's organisations in the Making Life Better regular forums. Disability-proof existing Making Life Better indicators and continue to collect disaggregated data on experiences of d/Deaf and disabled people especially with regard to the social determinants of health. Review progress to date in implementing the strategy with the active involvement of d/Deaf and disabled people

Ensure that d/Deaf and disabled people have an opportunity to participate in the development and updates of guidance for health and social care providers

Contract d/Deaf and disabled people (including marginalised groups such as learning disabled people) to develop disability human rights and equality training which should be mandatory for healthcare providers and professionals working in the healthcare sector

5.6 Justice system

Issue

Deaf and disabled people in Northern Ireland experience significant challenges in accessing justice. These include barriers in making complaints or reporting rights violations (including to police and other relevant bodies), accessing legal advice and legal representation. They also experience barriers to having their voices heard in the justice system, including through limitations on who can give evidence in court, support and assistance to participate in the court process, and gaps in legal protection of their rights including the absence of hate crime laws. Further issues in securing access to justice include the continued use of fitness to plead determinations and the insanity defence.

Human Rights Obligations

Article 13 requires States to ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective participation in all legal proceedings, including at investigative and other preliminary stages. It also mandates the provision of training for all personnel involved in the administration of justice, including police and prison staff. The CRPD Committee has increasingly commented on cases where Deaf people are excluded from jury service. The main concern centres around the provision of ‘reasonable adjustments’, in particular, the presence of an interpreter or third party during jury deliberations. This has been the case in Northern Ireland where d/Deaf people who require an interpreter are effectively excluded from being a juror. In its examination of the UK, the CRPD Committee has called on the government to ensure that all persons with disabilities enjoy the right and are provided with adequate procedural accommodation within the justice system, and enable in particular d/Deaf persons, through the use of sign language interpreters, to fully and equally participate as jurors in court proceedings.

Barriers

While there are provisions for d/Deaf and disabled people to give evidence through intermediaries in criminal proceedings as witnesses (Criminal Evidence (Northern Ireland) Order 1999) and defendants (Justice Act (Northern Ireland) 2011), these provisions only apply to criminal justice proceedings and no similar provisions exist in civil proceedings (including hearings about anti-discrimination or equality issues) to support d/Deaf and disabled people’s participation in the administration of justice.

Existing research also indicates that intermediaries are still not widely used or available to d/Deaf and disabled people even in the criminal justice system.¹⁰⁴

Civil and criminal legal aid in Northern Ireland is very limited in its availability to d/Deaf and disabled people to pursue justice. In particular, as legal aid is not available for specific issues that adversely affect d/Deaf and disabled people – including procedures under the Mental Capacity Act and disability discrimination cases, this limits the potential for d/Deaf and disabled people to access justice. Even where d/Deaf and disabled people find legal representation, they may face further barriers in communicating with their legal representatives and communicating in legal processes such as in giving evidence to police or in court, including the availability of sign language interpretation or other communication supports (including augmented and facilitated communication).

Measures

Action

Introduce legislation to extend legal aid to specific areas of relevance to d/Deaf and disabled people including equality/non-discrimination. Enable and fund d/Deaf and disabled people's organisations and other civil society groups to pursue legal redress for d/Deaf and disabled people

104 Independent Mechanism for Northern Ireland, Jurisdictional 'Parallel' Report on implementation of the UN CRPD in Northern Ireland (IMNI, 2017) [https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI_CRPD_ParallelJurisdictionalReport_WorkingPaper\(Aug17\).pdf](https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI_CRPD_ParallelJurisdictionalReport_WorkingPaper(Aug17).pdf) accessed 20 November 2020

Action

Consult on the development of legislation to close gaps in securing justice for d/Deaf and disabled people, e.g. hate crime

Contract d/Deaf and disabled people to design inclusive training on access to justice and disability for police and prison staff

Develop training in partnership with d/Deaf and disabled people for legal practitioners on securing access to justice

Designate a disability access officer for all court levels and tribunal sittings and publish information online in accessible formats about the reasonable accommodations available

Deaf people should be facilitated to fulfil their role as a member of the jury when called and provided with a sign language interpreter or captioning in all cases when requested including for the purpose of jury deliberations

The Registered Intermediary Scheme should be inclusive of d/Deaf people. Deaf people should be given the opportunity to train as a Registered Intermediary with the aim of supporting d/Deaf people during police interview and in court

5.7 Political and Public Life

Issue

Deaf and disabled people in Northern Ireland are underrepresented in political and public life. There is an under-representation of d/Deaf and disabled people in applications and appointments to public roles (including government public appointments). DPOs have noted that there is limited progress in the development of “public life opportunities” for d/Deaf and

disabled people beyond the formal public appointments process with respect to public authorities (with notable exceptions) obligations under the “disability duties.”¹⁰⁵ Ensuring that personal assistance and other support is available and funded for disabled candidates, appointees and office holders is essential to level the playing field. Legal and policy barriers, including those based in disability benefits systems, must be addressed.

Human Rights Obligations

The CRPD Committee highlights the importance of the right to participate in political and public life in General Comment No. 7 regarding the significance of d/Deaf and disabled people’s participation in decision making: “The right of persons with disabilities to participate in political and public life (Article 29) is of extreme importance in ensuring the equality of opportunity for persons with disabilities to fully and effectively participate and be included in society. The right to vote and be elected is an essential component of the right to participate, as elected representatives decide on the political agenda and are key in ensuring implementation and monitoring of the Convention, advocating for their rights and interests”.¹⁰⁶

105 Independent Mechanism for Northern Ireland, Jurisdictional ‘Parallel’ Report on implementation of the UN CRPD in Northern Ireland (IMNI, 2017) 77 [https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI_CRPD_ParallelJurisdictionalReport_WorkingPaper\(Aug17\).pdf](https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/IMNI_CRPD_ParallelJurisdictionalReport_WorkingPaper(Aug17).pdf) accessed 20 November 2020

106 UN Committee on the Rights of Persons with Disabilities, General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/GC/7), para. 88

The CRPD Committee, in its Concluding Observations on the United Kingdom stated that it was: “concerned at the lack of information on accessibility and reasonable accommodation for persons with disabilities, during all stages of the electoral cycle, including the facilitating of their exercise of the right to vote, vote in private and be assisted by an assistant of one’s own choice.”¹⁰⁷

Barriers

The Equality Commission for Northern Ireland has highlighted that participation of d/Deaf and disabled people in political and public life as a key inequality concluding that while “research in relation to voting registration and exercise of voting rights is limited, it does consistently highlight those with disabilities as facing barriers, and also highlights socio-economic disadvantage as a contributory factor.”¹⁰⁸

107 UN Committee on the Rights of Persons with Disabilities, Concluding Observations on the First Periodic Report of the United Kingdom of Great Britain and Northern Ireland 2017 (CRPD/C/GBR/CO/1), para. 60. Equality Commission of Northern Ireland, ‘Key Inequalities in participation in Public Life’ (ECNI, 2018) <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/ParticipationInPublicLife-Statement.pdf> accessed 20 November 2020

108 Equality Commission of Northern Ireland, ‘Key Inequalities in participation in Public Life’ (ECNI, 2018) <https://www.equalityni.org/ECNI/media/ECNI/Publications/Delivering%20Equality/ParticipationInPublicLife-Statement.pdf> accessed 20 November 2020

The Electoral Commission's research cited examples of complicated registration requirements, inaccessible polling stations, a lack of disability awareness of polling staff, and the need for more information on what to expect when voting, and also identified barriers to communication issues such as the lack of sign language interpreters.¹⁰⁹ An access fund is available to support elected representatives with disabilities in England and Scotland and is currently being considered in Wales to encourage greater involvement of d/Deaf and disabled people to stand for elections. No such type of fund is available in Northern Ireland.¹¹⁰

Measures

Action
See recommendations under the Equality and Non-Discrimination section of this report as they relate to the public sector disability duties
Seriously review and develop an action plan to challenge the existing social security legislation which limits the genuine opportunity for d/Deaf and disabled people to participate in the public appointments process, including the opportunity to receive remuneration as appropriate on an equal basis with others not in receipt of welfare benefit

109 Ibid

110 Cabinet Office, 'A Call for Evidence: Access to Elections: Government Response' (Cabinet Office, August 2018) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/736710/Government_response_to_the_Call_for_Evidence_on_Access_to_Elections_.pdf accessed 20 November 2020

Action

Review the essential job criteria for public appointments removing additional burdensome qualifying criteria not essential to the successful appointments of d/Deaf and disabled people - for example the value of lived experience, their service to the community over third level qualifications and high level governance (the latter requirement can be learned with relevant support and induction training).

5.8 Emergency planning

Issue

Emergency Planning and preparedness measures for d/Deaf and disabled people in Northern Ireland are not formalised and mainstreamed, they thus fail to appropriately involve d/Deaf and disabled people and their organisations. The impacts of this both locally and globally during the COVID-19 pandemic have been wide and varied but the constant has been a feeling by many d/Deaf and disabled people that they are being forgotten about¹¹¹.

Global research from the COVID-19 Disability Rights Monitor indicates that during the pandemic there have been: inadequate measures to protect persons with disabilities in institutions, significant and fatal breakdown of community supports, disproportionate impact on underrepresented groups

111 The Impact of Covid-19 on Disabled People in Northern Ireland, Crawford, Fitzsimons, O'Neill (2020) Available at:
<https://www.communityni.org/sites/default/files/2020-09/DANI%20COVID-19%20REPORT%20-%20Executive%20Summary%20FINAL.pdf>

of persons with disabilities and denial of access to healthcare.¹¹²

The same report also highlights some promising practices from around the world that include persons with disabilities and/or their representative organisations in inclusive COVID-19 responses to the crisis. In the absence of inclusive government measures, persons with disabilities and their representative organisations led and advocated for more disability-inclusive responses to the pandemic.

Human Rights Obligations

Our principle international obligation in relation to protection and safety of d/Deaf and disabled people in situations of risk, including armed conflict, humanitarian emergencies and natural disasters is found under CRPD Article 11:

‘States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.’¹¹³

112 COVID-19 Disability Rights Monitor, Disability rights during the pandemic A global report on findings of the COVID-19 Disability Rights Monitor (22 October 2020) <https://covid-drm.org/assets/documents/Disability-Rights-During-the-Pandemic-report-web.pdf> accessed 11 December 2020

113 United Nations Convention on the Rights of Persons with Disabilities Article 11 Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-11-situations-of-risk-and-humanitarian-emergencies.html>

Barriers

Barriers faced vary in respect of the nature and scale of the emergency unfolding. Time and time again globally it is recognised that d/Deaf and disabled people are disproportionately impacted by emergency situations. These situations therefore exacerbate the marginalisation of an already hugely socially and economically disadvantaged group of people.

Measure

Action
Establish and resource a cross departmental emergency planning disability advisory panel comprised of suitably qualified d/Deaf and disabled people and their organisations

6.0 Intersectionality

6.1 Children and young people

Issue

The intersectionality of childhood and age means that children with disabilities and their families experience specific and multiple disadvantages. This also means that d/Deaf and disabled children can fall between two stools and they have traditionally been excluded from childhood policies and strategies that focus on the mainstream child while disability related policies and strategies have tended to focus on disabled adults. According visibility to the experiences, specific needs and rights of d/Deaf and disabled children and their families across both childhood and disability strategies is therefore important.

The Northern Ireland Children's Strategy 2019-2029 notes that 'Departments will aim to take into account the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the recommendations in the 2017 Concluding Observations in developing their policies and services'. The strategy makes a commitment to work collaboratively to improve services for children and young people with a disability and with complex health care needs and/or life limiting conditions, and their families and carers across eight broad areas.

Human Rights Obligations

Article 7 of the CRPD makes it clear that children with disabilities have the same rights as all other children. Article 7(2) states that, in all actions concerning children with disabilities, their best interests must be a primary consideration. Significantly Article 7(3) establishes that children with disabilities have the right to express their views on all matters affecting

them and for these views to be given due weight. They are also entitled to disability and age appropriate assistance to enable them to express their views. Deaf and disabled children are also entitled to rights under the remainder of the CRPD as well as the UN Convention on the Rights of the Child (CRC). Examples of other rights include the right to education (see above), accessibility, and the right to play, recreation and leisure.

Deaf and disabled children are also entitled to rights under the remainder of the CRPD as well as the UN Convention on the Rights of the Child (CRC). In addition to the aforementioned rights which are also set out in the CRC, Article 23 of the CRC maps out the broad principles that must guide states in their provisions for d/Deaf and disabled children by addressing the rights of children with disabilities to, among others, enjoy a ‘full and decent life’ ‘with ‘dignity’, ‘self-reliance’, and ‘active participation in the community’. It also obliges States to extend ‘appropriate assistance’ to the child and those responsible for his or her care. This extension to persons other than children exemplifies the need for states to support the family structure.¹¹⁴ Article 23(3) of the CRC also provides guidance relating to the term ‘assistance’ by listing a range of services and activities to which children with disabilities are required to have effective access, including education, healthcare, training, rehabilitation, preparation for employment and recreation. Article 23(3) also creates a presumption that assistance must be provided ‘free of charge whenever possible’. The CRC Committee has elaborated upon the rights of children with disabilities in its General Comment 9.¹¹⁵ In particular, the CRC Committee has emphasised the importance of early intervention for

114 Bronagh Byrne The Rights of Children with Disabilities in J. Tobin ‘A Commentary on the UNCRC’ (Oxford University Press, 2019)

115 Committee on the Rights of the Child (2006) General Comment No. 9: The rights of children with disabilities. CRC/C/GC/9

d/Deaf and disabled children, calling on states to establish early intervention services that are community- and home-based, and easy to access. Furthermore, that links are established between early intervention services, pre-schools and schools to facilitate the smooth transition of the child.¹¹⁶ Critical to this and supports for d/Deaf and disabled children more generally is effective coordination and cooperation between services.

Barriers

There is a significant lack of data on the lived experiences of d/Deaf and disabled children. We simply do not know how many d/Deaf and disabled children there are in Northern Ireland. This makes appropriate planning of services, supports and provisions incredibly challenging.¹¹⁷ Available research suggests that families with d/Deaf and disabled children in Northern Ireland are more likely to live in poverty compared to families of children without disabilities.¹¹⁸ Identifying the true levels of child poverty in the context of disability is deeply problematic due to the extra costs of disability that many families experience, and because disability benefits continue to be counted as ‘disposable income’ when measuring poverty.¹¹⁹

¹¹⁶ Ibid, para 56

¹¹⁷ Children’s Law Centre (2013) Summary of Issues Raised in Response to OFMDFM Consultation on “A Strategy to Improve the Lives of Disabled People 2012–2015”

¹¹⁸ Bronagh Byrne, Child Poverty and Disability’ in Beneath the Surface: Child Poverty in Northern Ireland (CYPAPG 2014)

¹¹⁹ Ibid; Monteith, M., Casement, E., Lloyd, K. and McKee, P. (2009) Taking a closer look: Child Poverty and Disability, November Briefing, Belfast: Save the Children/Family Fund

Research also consistently shows that d/Deaf and disabled children are less likely to be involved in decision-making processes compared to children without disabilities and that they face a range of barriers in accessing services and supports that are both age appropriate and accessible.¹²⁰ While actions have been taken to support access to play facilities for d/Deaf and disabled children this has not been inclusive of all d/Deaf and disabled children with a study by Mae Murray showing that almost a third of families travelled up to an hour and a half out of their own council area to access suitable fixed play provision and 50% of respondents stated that they need access to a Changing Places toilet.¹²¹

The ‘Still Waiting’ report by NICCY¹²² highlighted that generic Child and Adolescent Mental Health Services (CAMHS) were not accessible to young people with learning disabilities. The review found that mental health problems for young people with a learning disability are often caused, or exacerbated by, the barriers and discrimination they face in day to day life. There is a lack of data on access to CAMHS services for other young d/Deaf and disabled people including young people who require sign language access.

Students with any special educational need or a disability are vulnerable to bullying. Research indicates that a greater proportion of pupils with a disability, particularly Year 9 students, reported they had been bullied at school in the previous couple of months ‘at least once or twice’ than pupils

120 IMNI (2017) Parallel Jurisdictional Report to the CRPD Committee

121 Mae Murray Foundation (2020) Are Play Spaces Accessible to All?

122 Northern Ireland Commissioner for Children and Young People (2018) Still Waiting? A rights based review of mental health support and services for children and young people in Northern Ireland. Belfast: NICCY

without a disability. A report by the ELBs also notes a clear link between the incidence of bullying and SEN.¹²³

Significant concerns across the lives of d/Deaf and disabled children have been highlighted by the Children with Disabilities Strategic Alliance in both their 2012 and 2016 manifestos.¹²⁴

These include the limited support services for families and an absence/lack of community based services for children with disabilities, particularly those children with complex needs and which can contribute to family stress and breakdown, deteriorating health of parents/carers, increased risk of children being placed in care and deteriorating emotional and social development for disabled children and their siblings.¹²⁵

123 RSM McClure Watters (2011) The nature and extent of pupil bullying in schools in the North of Ireland. DENI:
Bangor, Northern Ireland Education and Library Boards (2010) It's Good to Listen – Experiences of Pupils with Special Educational Needs

124 Children with Disabilities Strategic Alliance (2012) CDSA Manifesto;
Children with Disabilities Strategic Alliance (2016) CDSA Manifesto updated 2016-2020

125 Ibid; Mencap (2006) Breaking point: families still need a break.
Available at https://www.mencap.org.uk/sites/default/files/2016-07/Breaking%20Point%20Families_still_need_a_break%202006.pdf

In its 2017 Concluding Observations to the UK, the CRPD Committee expressed concern at: the lack of a policy framework addressing the poverty of many families with d/Deaf and disabled children; the failure to incorporate the human rights model of disability in public policies and legislation concerning d/Deaf and disabled children; the lack of monitoring mechanisms and reliable indicators; the absence of a general statutory duty upon public authorities to ensure adequate childcare for d/Deaf and disabled children; and the reported increase of incidents of bullying, hate speech and hate crime against d/Deaf and disabled children. This builds on the 2016 Concluding Observations to the UK from the CRC Committee which highlighted concerns that many children with disabilities do not see that their views are given due weight in making personal decisions in their life, including choice of support and future; and that provision of the support for transition to adulthood is ‘often neither sufficient, timely nor well-coordinated, and does not ensure fully informed decision by children with disabilities.’¹²⁶

Measures

The 2019 Children and Young People’s Strategy includes measures specific to d/Deaf and disabled children. It is important that the Disability Strategy acknowledges this and develops measures that allow actions across strategies to be aligned and maximised.

In addition, the Disability Strategy could adopt the following measures:

126 Committee on the Rights of the Child (2016) Concluding Observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland. CRC/C/GBR/CO/5

Action

Take action to collect, and resource the collection of data on the numbers of d/Deaf and disabled children in Northern Ireland and in line with the CRPD rights-based indicators

Ensure that the Disability Strategy and Children & Young People's Strategy are consistent and fully align with each other

Building on the Children & Young People's Strategy and Disability Strategy, develop a specific rights-based comprehensive action plan for the full and meaningful inclusion of d/Deaf and disabled children

Ensure that the Anti-Poverty Strategy is inclusive of families with d/Deaf and disabled children and takes account of extra costs of disability

Provide adjusted rates of disability poverty that excludes disability benefits from income

Provide and signpost d/Deaf and disabled children and their families with appropriate service through an agreed services pathway, including information, peer support, advice and advocacy services

Provide d/Deaf and disabled children with a comprehensive and integrated package of services for transition to adulthood, from a sufficiently early stage, by coordinating legislation, policy and programmes across relevant sectors, and ensure fully informed decisions by children with disabilities on their personal choice in the transition, by involving them in the design of services and by providing advice and information on available options

Action

Ensure d/Deaf and disabled children are supported (both in terms of human assistance and financial investment in appropriate supports) to express their views and to have their views given due weight in all decision-making that affects them, including on access to and choice of personal support and education

Take specific measures to prevent bullying against d/Deaf and disabled children

Agree a Short Breaks policy between the Department of Health, health agencies and children with disabilities and their families. This should not be restricted to overnight stays but include breaks that are fun, developmental, work for d/Deaf and disabled children and their families and are available on an equitable basis across Northern Ireland

Ensure sufficient and disability-sensitive childcare as a statutory duty

Develop guidance on inclusive play for d/Deaf and disabled children

Take forward the following five recommendations from NICCY (2018) 'Still Waiting' report (37-40):

A comprehensive and integrated mental health service model across Northern Ireland for children and young people with a learning disability should be agreed and implemented. This model must ensure that young people with a learning disability can access comparable services and support as young people without a disability

Assess how widespread the practice of determining eligibility of access to specialist mental health services (CAMHS) solely or mainly on the basis of IQ is, and take all necessary measures to ensure that access to services is always on the basis of need

Action

A comprehensive review of community based emotional, mental and behavioural support services for young people with a learning disability should be carried out without delay

Immediate steps must be taken to ensure that all detentions of children and young people in the Iveagh Centre under the Mental Health (Northern Ireland) Order 1986 is proportionate and appropriate

In addition, the Department of Health should assess the extent to which CAMHS is accessible for all other children and young d/Deaf and disabled people including those who require access to sign language

6.2 Gender equality

Issue

Deaf and disabled women and minority genders (including trans, intersex and non-binary people) face specific barriers in realising their human rights in Northern Ireland. The Northern Ireland Disability Strategy must take an intersectional approach to discrimination and develop gender-sensitive approaches to respecting the human rights of all d/Deaf and disabled people. This includes the right of d/Deaf and disabled people to express their gender identity and to have their gender recognised. Community services for women and minority genders must be fully accessible to d/Deaf and disabled people, and disability services and supports must be accessible and responsive to the needs of disabled women and minority genders.

Human Rights Obligations

Article 6 CRPD recognises that disabled women and girls are subject to multiple discrimination, and requires states to take action to address this.

General Comment No. 3 of the CRPD Committee also recognises that the term ‘disabled women’ in Article 6 includes transgender and intersex women among others.¹²⁷ The General Comment also acknowledges specific human rights violations which are experienced disproportionately by disabled women, including forced contraception and sterilisation, female genital mutilation, the performance of surgery or treatment of intersex children without informed consent, and denials of legal capacity which result in disabled women being denied the opportunity to make decisions about their fertility and reproductive autonomy on an equal basis with non-disabled people.¹²⁸

Barriers

Reports indicate that health services available to women and minority genders, including maternity services, cervical and breast check and screening services, are not always provided in a manner which is accessible to all d/Deaf and disabled people or in a way which respects the autonomy and dignity of disabled women and minority genders. d/Deaf and disabled people who wish to apply for a gender recognition certificate in Northern Ireland are required to prove a diagnosis of gender dysphoria, which represents a medical model approach to gender identity.¹²⁹ By contrast for example in the Republic of Ireland, d/Deaf and disabled people do not have to prove a specific diagnosis in order to have their gender

¹²⁷ UN Committee on the Rights of Persons with Disabilities, General Comment No. 3 (2015) on women and girls with disabilities (CRPD/C/GC/3), para. 5.

¹²⁸ Ibid, paras. 32 and 44

¹²⁹ See NI Direct, ‘Gender Recognition’ (NI Direct, 2020) <https://www.nidirect.gov.uk/articles/gender-recognition> accessed 20 November 2020

recognised, and instead can self-identify.¹³⁰ Disabled trans people in Northern Ireland have also expressed concerns that their disability is sometimes used as a justification not to grant them gender recognition – on the basis that some d/Deaf and disabled people do not have the autonomy to make decisions about their gender.¹³¹ This represents a clear violation of d/Deaf and disabled people’s right to exercise legal capacity on an equal basis with non-d/Deaf and disabled people as protected in Article 12 CRPD.

Measures

Action

Reform the provisions of the Gender Recognition Act 2004 as they apply to Northern Ireland to remove pathologizing approaches to gender identity and ensure that d/Deaf and disabled people can apply for gender recognition on an equal basis with others

Review and revise existing health policies and practices targeted at women and minority genders (especially maternity services, and health screening services) to ensure these are provided in an accessible manner for d/Deaf and disabled people

Support the active involvement of disabled women and minority genders in the design, implementation and monitoring of the forthcoming Gender Equality Strategy Northern Ireland

130 Gender Recognition Act (Ireland) 2015, s.10

131 Ellen Murray, ‘The Wrong Decisions: Trans Rights and Disability’ (YouTube, 18 August 2019), <https://ellenfromnowon.co.uk/wrongdecisions/> accessed 20 November 2020

6.3 Ethnic minority groups

Issue

The link between disability, poverty and economic deprivation is well established.^{132 133} What is less clear, especially within a Northern Ireland context, is the degree to which other factors including, (but not limited to) ethnicity intersect with disability and affect poverty, social mobility and inclusion. There is a need to establish the degree to which d/Deaf and disabled people who belong to ethnic minority communities within Northern Ireland are facing challenges/barriers and discrimination in respect of realising their rights as citizens. Barriers that are not only common to all d/Deaf and disabled people, but also those specific to their community. It can be said with some confidence that d/Deaf and disabled people from ethnic minority communities will face many of the same barriers in respect of all d/Deaf and disabled people. It is also highly likely however that the complex barriers their communities face add an additional layer, and opportunity for failure to realise their rights.

132 Eurostat: Disability Statistics – Poverty and Income Inequalities
Available at: https://ec.europa.eu/eurostat/statistics-explained/index.php/Disability_statistics_-_poverty_and_income_inequalities

133 Being Disabled in Britain: A Journey Less Equal, EHRC, (2017) Available at: <https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf>

Human Rights Obligations

There is no one specific principle international obligation in relation to disability and ethnicity, rather a broad number including Article 5 CRPD¹³⁴ Equality and Non Discrimination, Article 12¹³⁵ Equal recognition before the law & Article 18¹³⁶ Liberty of Movement and Nationality.

Barriers

While there is data in respect of poorer outcomes for ethnic communities in Northern Ireland¹³⁷, there is little or no easily accessible disaggregated data on d/Deaf and disabled people within these communities. When data is available it points to significantly poorer outcomes and in some cases substantially heightened risk. Data on mental health within the travelling community for example, suggests traveller men are 6.6 times more likely to die by suicide than settled men¹³⁸. The ongoing marginalisation and failure

134 United Nations Convention on the Rights of Persons with Disabilities, Article 5 Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

135 Ibid 3 - Article 12

136 Ibid 3 –Article 18

137 Poverty and Ethnicity: Key Messages for Northern Ireland, Lucas & Jarman, JRF, (2016) Available at: <https://www.jrf.org.uk/report/poverty-and-ethnicity-key-messages-northern-ireland>

138 Evidence Brief: Mental and Health and Suicide in the Traveller Community, NSRF, University College Cork (2015) Available at: <https://www.nsr.ie/wp-content/uploads/Briefings/Evidence%20brief%20NSRF%20-%20Mental%20Health%20and%20Suicide%20among%20Travellers%2002-07-2015.pdf>

to include these communities, and the subsequent lack of involvement within the policy and programme development sphere has significant widespread impact¹³⁹, the adage of ‘Nothing About Us Without Us’ remains.

Measures

Action
Proactively encourage and use positive action measures to recruit those with disabilities from ethnic minority communities into public service roles
Ensure that existing current cross departmental service provision which is targeted at d/Deaf and disabled people, understands and flexes to the intersectionality of this community. Review and improve these services with the lived experience input of disabled individuals from these communities
Gather better data to understand how known barriers affect those d/Deaf and disabled people from ethnic minority communities and gather data to understand the unique barriers that they face
Support 3rd sector organisations to refine existing services to be more inclusive of d/Deaf and disabled people from ethnic minority communities and resourcing the piloting of new bespoke projects which actively target known challenge areas arising from data capture or what the communities themselves are reporting

139 Health Intelligence Briefing: Mental Health of Travellers, Public Health Agency Available at: <http://www.mhfi.org/travellermentalhealth.pdf>

6.4 LGBTQI+ community

Issue

Deaf and disabled people in the LGBTQI+ community in Northern Ireland are often invisible.

Human Rights Obligations

According to Article 25 CRPD, d/Deaf and disabled people are entitled to access to sexual health services on an equal basis with non-disabled people. General Comment No. 3 and General Comment No. 7 recognise that LGBTQI+ people include d/Deaf and disabled people and that support for d/Deaf and disabled people to express their sexuality and access services must be provided.

Barriers

Services provided for the LGBTQI+ community are often inaccessible to d/Deaf and disabled people and disability supports are often unresponsive to the needs of LGBTQI+ people. There is a need for greater alignment between these services and supports to ensure that LGBTQI+ spaces are disability-inclusive, and that disability spaces are LGBTQI+ inclusive.

Measures

Action
Provide support for d/Deaf and disabled people to express and explore their sexuality on an equal basis with others
Resource and train DPOs and the wider disability sector to be inclusive of d/Deaf and disabled people with different sexual orientations

Action

Resource and support LGBTQI+ organisations to fully include d/Deaf and disabled people and promote their participation in their organisations

Equality training commissioned by public sector and other organisations on LGBTQI+ issues must be disability-inclusive

The LGBTQI+ Strategy must take a disability inclusive approach

6.5 Asylum seekers, refugees, migrants

Issue

Deaf and disabled asylum seekers, refugees and migrants face multiple and complex barriers in realising their human rights in Northern Ireland.

Organisations representing asylum seekers, refugees and migrants need further resources and support to ensure their services are accessible to d/Deaf and disabled people in these communities, and public sector providers also need to design supports for this group in a manner that is accessible to d/Deaf and disabled people.

Human Rights Obligations

All the obligations in the CRPD apply equally to d/Deaf and disabled asylum seekers, refugees and migrants. Physical accessibility of housing accommodation provided to d/Deaf and disabled asylum seekers, refugees and migrants face multiple and complex asylum seekers, refugees and migrants needs to be further addressed along with accessible information and communication d/Deaf and disabled asylum seekers, refugees and migrants on their rights in Northern Ireland.

Barriers

There is a marked absence of any publicly available data in respect of disabled asylum seekers, refugees and migrants in Northern Ireland. As immigration is not a devolved matter, whatever data is recorded and retained is held by the UK Government. The data that is released is not disaggregated by region¹⁴⁰.

Measures

Action
Work with d/Deaf and disabled asylum seekers, refugees and migrants and their organisations to understand the disability-specific immediate short term barriers that they are facing as they enter the Northern Ireland ‘system’
Review current public, and publicly funded provision to ensure it adapts to the needs of d/Deaf and disabled people and avoids creating any further vulnerability and risk
Ensure that planning and onward work with those who are successful in their applications is joined up across departments and organisations
Ensure as much as possible that those d/Deaf and disabled people whose applications are unsuccessful are supported/protected on their exit from the country

140 Refugees and Asylum Seekers in Northern Ireland, Northern Ireland Assembly Available at: <http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2014/ofmdfm/6314.pdf>

6.6 Older People

Issue

The rights of older d/Deaf and disabled people are often overlooked. The Northern Ireland Survey of Activity Limitation and Disability (NISALD) (2008) estimates that approximately 60% of those aged 70 and above in NI are disabled, while globally it is estimated that almost half of those aged 60 and over have some form of disability.¹⁴¹ Deaf and disabled older people constitute two groups: those who acquire a disability as they get older; and those who are ageing with a disability. Like other groups of d/Deaf and disabled people, d/Deaf and disabled older people will experience similar general barriers as each other, but also distinct barriers that arise due to the intersection of disability and age. Higher life expectancy generally means that the numbers of d/Deaf and disabled people will continue to increase.

Human Rights Obligations

The CRPD contains a number of Articles which highlight the intersectionality of ageing and disability. These include: Article 8 (awareness-raising); Article 9 on accessibility, Article 13 (Access to justice); the importance of age-sensitive assistance and age-sensitive protection services in Article 16 (Freedom from exploitation, violence and abuse); Article 19 on living independently and being included in the community; Article 20 on personal mobility and Article 25 on health. States are also called upon to ensure access by older persons with disabilities to social protection programmes and poverty reduction programmes in Article 28 (Adequate standard of living and social protection). It has been noted that despite the almost

¹⁴¹ Conference of States Parties to the CRPD Committee (2020) Addressing the rights and needs of older people with disabilities: ageing and demographic trends. CRPD/CSP/2020/3

universal ratification of the Convention on the Rights of Persons with Disabilities and the steps the States parties have taken to implement it, many older persons with disabilities continue to experience barriers to the full enjoyment of their rights.¹⁴²

Barriers

There is a distinct lack of evidence on the lived experiences of older d/Deaf and disabled people in Northern Ireland. Older d/Deaf and disabled people have yet to be systematically recognised in Northern Ireland as a distinct population group. Instead they are seen either as part of a general group of d/Deaf and disabled people, or as older people, but not as both. This means their specific needs are not targeted or addressed. For example, the Active Ageing Strategy 2016-2022 for Northern Ireland appears to view ‘older people’ as a homogenous grouping. The panel is concerned that older d/Deaf and disabled people are thus largely invisible. The panel is also concerned that some d/Deaf and disabled people may lose entitlement to disability services or supports such as personal assistants when they reach 65 and transfer to older people’s services. Given that the numbers of older d/Deaf and disabled people will continue to grow, it is critical that they are able to access services that are both age and disability appropriate, and not simply one or the other.

¹⁴² Ibid para 5

Measure

Action
Gather better data to understand the lived experiences and barriers that older d/Deaf and disabled people encounter
Collect data on the numbers of older d/Deaf and disabled people in Northern Ireland
Ensure that older d/Deaf and disabled people have the same entitlements as younger d/Deaf and disabled people to services and supports; for example to personal assistants
Ensure that services and supports are available to older d/Deaf and disabled people and that these are both age and disability appropriate
Ensure that future Ageing Strategies and related policies recognise the particular experiences of older people who are d/Deaf and disabled

7.0 Conclusions

The role of the Expert Panel for the Disability Strategy is to advise the Department for Communities on the priorities and themes upon which a cross-departmental Disability Strategy and supporting action plan should be developed. Throughout the short time period in which this review was conducted, the Panel has sought to make the best use of existing available evidence to inform its recommendations. It will be of little surprise to those reading this report that there remain significant gaps in up to date, consistent and disaggregated data on d/Deaf and disabled people's experiences of their rights in Northern Ireland. This reinforces further the need for the overarching framework on which this report and its recommendations are based; that is, the UN Convention on the Rights of Persons with Disabilities.

The very first premise of this report is that all d/Deaf and disabled people in Northern Ireland – whether child or adult and irrespective of impairment or background - are, fundamentally, rights-holders, and should be treated on the basis of the principles of fairness, respect, dignity, equality and autonomy. With this in mind, the substantive sections of this report, and the recommendations that flow from each, are based upon the general principles of the CRPD.

In our view the next Disability Strategy must be explicitly rights-based and act as the central tool for implementing the CRPD in Northern Ireland. Deaf and disabled people have a critical role to play in the development, implementation and monitoring of the Disability Strategy. Our lived experiences are not homogenous. The rich and diverse lived experiences of the disability community in Northern Ireland must be given voice in the development of responsive legislative and policy solutions and appropriate structures, services and infrastructure. In short, there must be **nothing about us, without us**.

The Expert Panel is acutely aware that the report does not cover everything and does not address each issue in as much detail as we would have liked. The limited time available to complete this report has been undoubtedly challenging. We hope that the recommendations contained herein will provide the Disability Strategy Co-design Group with sufficient material to consider in its work. We are mindful that translating our recommendations will not be an easy task. Nonetheless, we trust that d/Deaf and disabled people and their representative organisations will take the leading role going forward in making these rights real.

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