Progress Towards the Implementation of the UNCRPD in Northern Ireland

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Equality Commission
FOR NORTHERN IRELAND

Disability
Action

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List of Abbreviations	
ASD	Autism Spectrum Disorder
DoH	Department of Health (NI)
DfC	Department for Communities (NI)
DDA	Disability Discrimination Act (DDA) 1995
DLA	Disability Living Allowance
DNR	Do Not Resuscitate
DPO	Disabled People's Organisation
DWP	Department of Work and Pensions
ECNI	Equality Commission for Northern Ireland
ECT	Electro-Convulsive Therapy
HSCT	Health and Social Care Trust
ILF	Independent Living Fund
IMNI	Independent Mechanism for Northern Ireland
NI	Northern Ireland
NIHRC	Northern Ireland Human Rights Committee
TEO	The Executive Office
PIP	Personal Independence Payment
PfG	Programme for Government
PPR	Participation and the Practice of Rights
PSNI	Police Service of Northern Ireland
RNIB	Royal National Institute of Blind People
RNID	Royal National Institute for Deaf People now known as Action on Hearing Loss
RQIA	Regulation and Quality Improvement Authority
SEN	Special Educational Needs

“Enough with lip service and nods to what should be done - try doing something to the benefit of disabled people”

Disabled woman with a long-term health condition, aged 65+

Executive Summary

Introduction

This report is a review of the work on the United Nations Convention ('the Convention') on the Rights of Persons with Disabilities (UNCRPD)[1] undertaken within Northern Ireland (NI). The UNCRPD[2] is a global international human rights treaty setting out the human rights of deaf and disabled people. The review was undertaken by Disability Action on behalf of the Equality Commission for Northern Ireland. The Equality Commission for Northern Ireland, as part of the Independent Mechanism for Northern Ireland,[3] has contracted research to develop a series of expert papers to set out evidence of any substantive shortfalls of public policies and programme delivery set against the key requirements of the UNCRPD[4] which the UK Government signed up to in 2009.

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[1] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly.

[2] Ibid.

[3] The Independent Mechanism for Northern Ireland (IMNI), the Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission have been jointly designated as the focal point by the Northern Ireland Executive to promote, protect and monitor the implementation of the United Nation Convention on the Rights of Persons with Disabilities. Together with the Equality and Human Rights Commission in England and Wales and the Human Rights Commission in Scotland they are also part of the United Kingdom Mechanism (UKIM) are required to report progress to the UN Committee on the Rights of Persons with Disabilities on how well each of the devolved nations and the UK Government as a whole, are progressing with the with implementation of the UNCRPD.

[4] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly .

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)[5] is an international agreement drawn up by States with the involvement of d/Deaf and disabled people which affirms that deaf and disabled people have the same rights as non-disabled people. The implementation of the UNCRPD has been slow within the NI context. That said, the UNCRPD remains an important catalyst for social change with respect to the rights of d/Deaf and disabled people.

The Northern Ireland Context

The Assembly and Executive has experienced instability during the reporting period within this report. The collapse of the institutions in 2016 led to a legislative hiatus which further complicated the challenges within the region associated with the legacy of the recent conflict. NI as a region continues to experience significant challenges due to underfunding and the complexity associated with addressing legislative gaps and deficits which exist in the absence of agreement for a Single Equality Act.

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[5] Ibid.

The institutions became operational again in early 2020 but have faced ongoing challenges in the context of the ongoing Covid-19 crisis and the implications of Brexit. A political crisis emerged when the First Minister, Paul Givan, resigned on 3 February 2022 in protest of the lack of progress made within negotiations between the UK Government and the EU[6] with respect to the Northern Ireland Protocol[7].

At the time of writing the political institutions were unstable and while legislation in progress could proceed, the Executive cannot effectively function. The Northern Ireland (Ministers, Elections and Petitions of Concern) Act 2022[8] provides for an extension of the period of time to appoint Ministers before the Secretary of State is obliged to propose a date for an election[9].

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[6] Irish Times (2022): Paul Givan resigns as First Minister of Northern Ireland in DUP protocol protest (accessed 19 February 2022).

[7] DfEEU (2018): New Protocol on Ireland/Northern Ireland and Political Declaration. London: HMSO. Article 2 Rights of Individuals (accessed 29 November 2021).

[8] Northern Ireland (Ministers, Elections and Petitions of Concern) Act 2022 (accessed 13 February 2022).

[9] Explanatory Notes, Northern Ireland (Ministers, Elections and Petitions of Concern) Bill, p3 (accessed 13 February 2022).

Report on Progress by d/Deaf and Disabled People

A survey of individuals regarding the impact of the UNCRPD on the lives of d/Deaf and disabled people was undertaken between 10 November and 20 December 2021. The survey collected qualitative and quantitative data from 84 individuals, via a snowball sampling strategy, in partnership with DPOs and Civic Society across the region:

- 89% (74) of respondents felt that disabled people continue to find it difficult to find and keep a job;
- 88% (73) of respondents indicated that they believe there are negative attitudes and discrimination towards d/Deaf and disabled people in NI;
- 67% indicated that they did not believe that d/Deaf and disabled people are adequately protected against discrimination in NI;
- 82% of respondents reported that there were not enough opportunities for d/Deaf and disabled people to be involved in the planning process in response to Covid-19;
- 80% of respondents believed that there was not enough planning in place to protect d/Deaf and disabled people during the Covid-19 pandemic;
- 81% (67) of respondents believe that buildings, housing, and transport are inaccessible to d/Deaf and disabled people;

- 78% (65) of respondents did not feel that d/Deaf and disabled people have enough money to have a decent life;
- 76% (63) of respondents indicated that d/Deaf and disabled people do not have enough access to support to live independently;
- 72% (60) of respondents felt that d/Deaf and disabled people find it hard to get help and support when they have a legal problem;
- 63% (52) felt that there is not enough financial support for d/Deaf and disabled people when they are accessing justice in NI;
- 65% (54) of respondents felt that the rights of d/Deaf and disabled women were not given enough attention;
- 61% (51) of respondents felt that d/Deaf and disabled people still have problems voting in elections and taking part in politics;
- 59% (49) of respondents believe that children's rights are unprotected;
- 57% (47) of respondents indicated that they do not think that d/Deaf and disabled children and people are able to fully take part in education.

Qualitative data collected through the surveys provided rich data with respect to the current experiences of d/Deaf and disabled people within NI. Key themes emerging from the data demonstrated:

- the regression of the rights of d/Deaf and disabled people due to the ongoing damaging impact of austerity and welfare reform on the lives of d/Deaf and disabled people;
- extensive reports of experiences of discrimination;
- the negative impact of Covid-19 on the physical and mental health of d/Deaf and disabled people, the collapse of health and social care services, increased reliance on food banks, isolation, and continuing difficulties in accessing medicine and healthcare;
- concerns regarding Do Not Resuscitate Orders (DNRs);
- barriers in accessing healthcare;
- the lack of provision of social care which is resulting in d/Deaf and disabled people remaining within institutions and hospitals;
- the absence of d/Deaf and disabled people within Covid-19 planning and the lack of services and measures addressing the needs and requirements of d/Deaf and disabled people;
- the lack of opportunities for independent living experienced by many d/Deaf and disabled people within the region coupled with reductions in funding;

- barriers in accessing and continuing in education;
- concerns regarding the use of restraint in education settings;
- the absence of play and social experiences for d/Deaf and disabled children;
- poor availability of changing places toilets resulting in d/Deaf and disabled people having to change on dirty toilet or bathroom floors;
- ongoing stigma associated with mental health challenges;
- the lack of access to legal redress;
- the lack of access to hate crime advocacy;
- high levels of bullying and hate crime;
- high levels of abuse and violence;
- the lack of opportunities for d/Deaf and disabled people to participate in decision making, under-representation in politics and barriers to voting;
- the need for legislation to protect the rights of d/Deaf and disabled people and enforcement measures to effect change;
- Extensive evidence of experiences of employment and workplace discrimination;
- little or no access to accessible housing;

- the lack of accessible transport and barriers in access to forms of accessible transport which are currently available due to the need to pre-book, restricted timescales, or poor provision;
- challenges for people with hidden disabilities in terms of discrimination;
- the lack of voice for d/Deaf and disabled women;
- the absence of differentiated data;
- levels of frustration at the lack of progress to protect the rights of d/Deaf and disabled people.

Incorporation of the UNCRPD in Northern Ireland

Northern Ireland has yet to incorporate the UNCPRD into a law. There has been a persistent absence of concrete measures to incorporate the UNCRPD within NI coupled with a lack of indicators through which to evaluate progress. There is limited evidence of the adoption of a human rights-based approach to disability and an absence of participatory approaches which have delivered concrete outcomes to advance the rights of d/Deaf and disabled people, resulting in significant gaps in the implementation of the UNCRPD In Northern Ireland.

The continued lack of progress regarding the incorporation of the UNCRPD into law is linked to the continuing delays in the development and implementation of subsequent disability strategies and the absence of progressive change to improve the lives of d/Deaf and disabled people. The report of the Disability Strategy Expert Advisory Panel Report has concluded that the devolved administration in NI has not taken adequate steps to progress the implementation of the Convention[10]. The panel noted that the Convention is not directly incorporated into domestic law and that the NI Executive has not given the Convention due consideration in the development of policy and legislation[11] [12]. The Chief Commissioner of the Equality Commission for Northern Ireland has stated that lack of progress to close the gaps in legal protections between equality law in Northern Ireland and Great Britain has positioned the region in the "dark ages" with respect to equality to such an extent that there is a "serious risk of falling way behind, to not being a developed country".[13]

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[10] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.12 (accessed 10 October 2021).

[11] Ibid, p.12-14.

[12] Professor Brice Dickson has referred to the power of the Northern Ireland Assembly to incorporate international human rights conventions being overlooked. See: Dickson, B. (2021): Implications for the Protection of Human Rights in a United Ireland', *Irish Studies in International Affairs*, 2021, Vol. 32, No. 2, Analysing and Researching Ireland, North and South (2021), pp. 589-610. p.594.

[13] The Irish Times (2021): Northern Ireland 'in dark ages' in terms of equality laws, 20 October 2021 (accessed 5 November 2021).

The Report of the Disability Strategy Expert Advisory Panel provides a framework through which to address current gaps associated with the UNCRPD[14]. At the time of writing work with respect to the development of the Disability Strategy remained ongoing. There are concerns regarding the potential for the Strategy to be delivered within the current mandate due to the recent political crisis triggered by the resignation of the First Minister Paul Givan MLA, on 3 February 2022[15].

Although progress with respect to advancing the Disability Strategy should be acknowledged, the extent to which the recommendations of the Expert Panel and the Co-Design Group are to be reflected in the final Strategy remains to be seen. At the time of writing there is no coherent delivery plan to address the requirements of the Convention within the NI context.

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[14] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, pp.12-14 (accessed 10 October 2021).

[15] Irish Times (2022): Paul Givan resigns as First Minister of Northern Ireland in DUP protocol protest (accessed 19 February 2022).

Non-Compliance with the UNCRPD

There are several areas in policy, practice and legislation within NI which is non-compliant with the UNCRPD. These include The Mental Health and Capacity Act (2016)[16], inadequate protections against disability discrimination[17], the continued use of involuntary ECT[18], the use of restraint and seclusion in both health and educational settings[19], evidence of abuse and degrading treatment within institutional settings[20], inadequate play and leisure facilities for d/Deaf and disabled children[21], lack of access to appropriate toileting facilities[22], the under-representation of d/Deaf and disabled people in decision making[23], and increasing levels of disability hate crime[24].

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[16] Mental Capacity Act (NI) 2016 (accessed 3 November 2021).

[17] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.62 (accessed 10 October 2021).

[18] RQIA (2017): Annual Report on the Administration of Electroconvulsive Therapy in Northern Ireland, p.4 (accessed 29 December 2021).

[19] DoH (2021): Public Consultation on Regional Policy on the Use of Restrictive Practices in Health and Social Care Settings (accessed 14 December 2021).

[20] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, pp.49-54 (accessed 10 October 2021).

[21] Mae Murray Foundation (2020): Are Play Spaces Accessible to All? (accessed 26 December 2021).

[22] Ibid.

[23] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.109 (accessed 10 October 2021).

[24] PSNI (2021): Incidents and Crimes with a Hate Motivation Recorded by the PSNI: Update 30th June 2021 (accessed 4 November 2021).

Retrogression of Existing Rights

Concerns were raised about the retrogression of rights in the context of:

- the continued impact of Welfare Reform[25];
- reductions in social care funding[26];
- the closure of Independent Living Fund to new applicants[27];
- the continued lack of accessible transport and public services[28];
- the impact of Brexit on the retrogression of rights[29];
- the Impact of the Covid-19 crisis including the collapse of services, inappropriate us of DNRs and withdrawal of medical treatment[30];
- the ongoing impact of the reduction of public finance budgets and austerity on public service delivery[31];
- under-resourcing of DPOs[32].

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[25] EHRC (2020): The cumulative impact of tax and welfare reforms, pp.15-16.

[26] British Medical Association (2020): Social care in Northern Ireland.

[27] O'Neill, E. and Fitzpatrick, F. (2020): Independent Living Fund Northern Ireland Impact Evaluation, Foreword (accessed 5 Nov 2021).

[28] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.72 (accessed 10 October 2021).

[29] Prime Minister's Office (2017): Joint report on progress during phase 1 of negotiations under Article 50 TEU on the UK's orderly withdrawal from the EU, December 2017, London: HMSO, paragraph 53, p.8 (accessed 29 November 2021).

[30] ECNI (2020): People with disabilities must not be left behind by response to COVID-19 (accessed 28 December 2021).

[31] Women's Policy Group (NI) (2020): Covid-19 Feminist Recovery Plan: Summary of Recommendations. 4.1, 1.2, 1.4, 3.2, 4.2, 2.3. (accessed 30 October 2021).

[32] Disability Action (2021): DPOs are chronically underfunded.

The NI Executive and Assembly yet to provide a strategy to prevent retrogression of the rights of disabled people. It is not clear, yet, what the outcomes of the Disability Strategy or the extent to which the UNCRPD will be embedded in the Strategy. The Disability Strategy Expert Advisory Panel have recommended that the Strategy explores ways in which the UNCRPD can best be given legal effect in Northern Ireland[33].

The Right to Life

The right to life is a fundamental principle of international human rights law. Covid-19 has brought the Right to Life of d/Deaf and disabled people to the fore. A disproportionate number of d/Deaf and disabled people have died due to Covid-19.

The Northern Ireland Statistics and Research Agency (NISRA) published an equality group analysis of wave one deaths due to Covid-19 which showed that disabled people were 40% more likely to die of Covid-19[34].

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[33] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.12 (accessed 10 October 2021).

[34] NISRA (2021): Covid-19 Deaths and Equality - Wave One (accessed 2 February 2021).

People with learning disability have experienced greater excess deaths from Covid-19 as well as being disproportionately affected by the lock-down procedures implemented by the UK Government and the devolved administration[35].

There have been instances in which medical treatment has been withheld or withdrawn from d/Deaf and disabled people with devastating impacts[36]. Disabled people and their families, including parents of autistic children and carers of people with learning disabilities, are reporting that they have been asked to complete Do Not Resuscitate (DNR) orders, in case they become critically ill, with no consultation[37].

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[35] ARC (NI) (2020): A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland p.16 (accessed 5 November 2021).

[36] Ruck Keene, A.C.E and Lee, A. (2019): Withdrawing life-sustaining treatment: a stock-take of the legal and ethical position. J Med Ethics. 2019 Dec;45(12):794-799 (accessed 26 December 2021).

[37] Byrne, B (ND): How the pandemic is further alienating the disabled community (accessed 21 December 2021).

Dignity, Choice and Control

Dignity, choice and control are of extreme importance to d/Deaf and disabled people. Dignity, choice and control are relevant to the following Articles of the UNCRPD: Article 12 Equal recognition before the law[38], Article14 Liberty and security of person[39], Article15 Freedom from torture or cruel inhuman or degrading treatment[40], Article 19 Independent Living[41], Article 23 Respect for home and family[42], Article 25 Health[43], Article 26 Habilitation and rehabilitation[44], and Article 28 Adequate Standard of Living[45].

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[38] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 12 (accessed 4 November 2021).

[39] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 14 (accessed 4 November 2021).

[40] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 15 (accessed 4 November 2021).

[41] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 19 (accessed 4 November 2021).

[42] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 23 (accessed 4 November 2021).

[43] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 25 (accessed 4 November 2021).

[44] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 26. (accessed 4 November 2021).

[45] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 28 (accessed 4 November 2021).

d/Deaf and disabled people raised the importance of choice and having control over their lives.

The key challenges raised by d/Deaf and disabled people include:

- implementation of the Mental Capacity Act (NI);
- the application of capacity legislation for children and young people[46];
- deprivation of Liberty[47];
- inhuman and degrading treatment[48];
- use of restraint and seclusion[49];
- abuse in residential and community settings[50];
- resettlement from long-stay hospitals and assessment and treatment units[51];
- enjoyment of home and family life[52];

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[46] Children's Law Centre (No Date): Written Evidence to the Ad Hoc Joint Committee on the Mental Capacity Bill, paragraph 2.2, p.2 (accessed 4 Nov 2021).

[47] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.37 (accessed 10 October 2021).

[48] Matthews, A (2015): Case Study: Law Centre for Northern Ireland Litigation in Respect of Resettlement into the Community (Muckamore Abbey)).

[49] BASW (NI) (2021): BASW NI policy statement concerning restraint and seclusion of children and young people in schools and educational facilities

[50] DoH (2020): Swann announces Public Inquiry into Muckamore Abbey Hospital (accessed 20 October 2021).

[51] NIHE (2014): The Hospital Resettlement Programme in NI after the Bamford Review (accessed 10 October 2021).

[52] Taggart, L. (2021): The impact of COVID-19 on people with learning disabilities in Northern Ireland: Implications for policy and practice, para 3.4.

- health inequalities and mortality rates[53];
- lack of habilitation for children and young people[54].

The Absence of Full Protection Against Disability Discrimination

d/Deaf and disabled people are concerned about the continued lack of progress within NI to provide comprehensive and adequate protection against multiple and intersectional discrimination. People in NI remain inadequately protected with respect to direct and indirect disability-based discrimination and against discrimination by association. There has been no movement to address the CRPD committee's recommendation to incorporate legal protection for multiple and intersectional disabilities[55]. d/Deaf and disabled people continue to have less protection that their UK counterparts[56].

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[53] NISRA (2021): Covid-19 Deaths and Equality - Wave One (2 February 2021).

[54] Belfast Telegraph (2015): Parents of visually-impaired children speak out over lack of specialist care (accessed 2 January 2022).

[55] 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, CRPD/C/GBR/CO/1, paragraphs 12 and 13, p.3 (accessed 5 November 2021).

[56] A review undertaken by the Equality Commission in NI in 2014 Cited in Byrne B., Harper, C., Irvine R. S., Russell, H. and Fitzpatrick, B. (2014): UNCRPD: Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD concluded (pp 56-57) that there were seven significant areas of divergence between GB and NI as the result of the lack of progress with respect to the protections within the Equality Act 2010 with NI including:

- definition of disability;
- perceived and associative discrimination;

The recommendations made by the Equality Commission in 2012[57] on the need to reform disability rights law have not been addressed. d/Deaf and disabled people in NI continue to be unprotected against indirect discrimination as a result of the outcome of the Malcolm Case[58]. In GB the Equality Act 2010 ensures that policies and practices, which unintentionally place d/Deaf and disabled people at a substantial disadvantage can be challenged. No comparable changes have been made in NI.

- indirect discrimination;
- discrimination arising out of disability;
- intersectional discrimination;
- access to remedies;
- increased powers for tribunals.

To date there have been no attempts by the NI Executive and Assembly to address the deficit in disability equality legislative provisions in Northern Ireland. The continued existence of diverse and separate pieces of legislation for different equality grounds results in the legal system in Northern Ireland being more complex, less accessible and, in some cases, affording weaker protections than in GB.

[57] Equality Commission for Northern Ireland (2012): Strengthening Protection for Disabled People Proposals for Reform, pp 3-8 (accessed 23 October 2021).

[58] EHRC (ND): The Malcolm Case (accessed 25 December 2021)

Accessibility

Articles of the UNCRPD including Article 4 General obligations[59], Article 9 Accessibility[60], 20 Personal Mobility[61], Article 24 Education[62], Article 27 Work and employment[63], Article 28 Adequate standard of living and social protection[64], Article 29 Participation in Public Life[65], Article 30 Participation in cultural life, recreation, leisure, and sport[66] all raise issues in relation to accessibility.

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[59] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 4 (accessed 4 November 2021).

[60] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 9 (accessed 4 November 2021).

[61] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 20 (accessed 4 November 2021).

[62] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 24 (accessed 4 November 2021).

[63] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 27 (accessed 4 November 2021).

[64] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 28 (accessed 4 November 2021).

[65] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 29 (accessed 4 November 2021).

[66] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 30 (accessed 4 November 2021).

Research has indicated that d/Deaf and disabled people experience significant barriers in accessing transport with respect to both physical accessibility and availability of service[67]. There are challenges with respect to disability awareness amongst staff employed by transport companies[68]. Whilst there have been some improvements[69] in recent years to transport infrastructure, but these are largely within the greater Belfast area and inequalities in access persist in other parts of the region[70]. There are ongoing challenges concerning public transport associated with service costs, provision, and timetabling[71], resulting in d/Deaf and disabled people having no choice but to access costly private solutions.

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[67] Harper, C., McClenahan, S., Byrne, B. and Russell, H. (2012): Disability Programmes and Policies how does Northern Ireland measure up? p.106

[68] IMNI (2017): United Nations Convention on the Rights of Persons with Disabilities Jurisdictional 'Parallel' Report on Implementation in Northern Ireland: Working Paper, p.22 (accessed 2 November 2021).

[69] Improvements in transport infrastructure include:

- the Disability Action Transport Scheme for people living in towns and cities who find it difficult to use public transport;
- Translink Easibus services which are mainly operational in Belfast provide accessible local bus services for (but not exclusively mobility impaired people;
- Shopmobility provides financial support for schemes in Ballymena, Belfast, Carrickfergus, Cookstown, Dungannon, Enniskillen, Lisburn, Derry/Londonderry (known as Foyle), Magherafelt, Newry and Omagh. These schemes lend manual and powered wheelchairs and powered scooters to members of the public with limited mobility to shop and use leisure and commercial facilities.

[70] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.78 (accessed 10 October 2021).

[71] Harper, C., McClenahan, S., Byrne, B. and Russell, H. (2012): Disability Programmes and Policies how does Northern Ireland measure up? pp.165-186 (accessed 10 October 2021).

Access remains an issue in many rural parts of Northern Ireland. d/Deaf and disabled people living in rural areas can face considerable challenges in accessing transport. Budget cuts to public services including accessible and affordable community transport in urban and rural areas the priority that should be given to making independent living a reality for all d/Deaf and deaf and disabled people has been undermined[72]. d/Deaf and disabled people living in rural areas face increased barriers to accessing services and transport[73].

d/Deaf and disabled people also face challenges due to inaccessible pedestrian environments which can restrict access to local services and facilities including transport and other opportunities. Challenges include the overuse of street furniture[74], pavement advertising and vehicle parking on pavements[75].

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[72] IMTAC (2019): IMTAC Annual Report, p.9 (accessed 12 December 2021).

[73] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.79 (accessed 10 October 2021).

[74] The use of street furniture has increased in the context of the pandemic as outside hospitality has been encouraged in the context of public health.

[75] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.79 (accessed 10 October 2021).

Participation in Decision Making

The importance of participation is core to the UNCRPD and represents a key theme within the UN Committees concluding remarks in 2017.[76] Participation and engagement were key priorities for people with disabilities and DPOs[77]. It is therefore essential NI Executive and Assembly improve the participation and engagement of d/Deaf and disabled people and their representatives at all levels in order to progress a right-based approach to disability policy and legislation. d/Deaf and disabled people need to have power and control over all areas of our lives.

The Rights of d/Deaf and Disabled Children

There has been little progress with respect to advancing the rights of d/Deaf and disabled children. d/Deaf and disabled children remain more likely to live in poverty in comparison with others[78]. There has been little with respect to developing a policy framework to address levels of poverty among families with children with disabilities.

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[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, CRPD/C/GBR/CO/1, paragraphs 9-10 .

[77] Flynn, E. (2011): From Rhetoric to Action, Cambridge University Press.

[78] Child Poverty Alliance (2014): Beneath the Surface (accessed 4 November 2021).

Incidents of bullying, hate speech and hate crime against d/Deaf and disabled children continue to increase. ECNI has identified the lack of accessible childcare as a particular issue for parents of d/Deaf and disabled children[79]. At the time of writing no action had been taken to address hate crime or hate speech directed at children and young people with disabilities.

The Disability Strategy Expert Advisory Panel report identifies a range of barriers that children with disabilities experience including the attainment gap between children with and without special educational needs, barriers in accessing essential support services, the challenges in the delivery of SEN, informal exclusions, and segregation[80].

There are concerns regarding the provision of adolescent mental health services to children with learning disabilities. The NI Commissioner for Children and Young People (2018) report 'Still Waiting' raises serious concerns about the accessibility of Child and Adolescent Mental Health Services by young people with learning disabilities[81].

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[79] ECNI (2013): 'Childcare – Maximising the Economic Participation of Women', page 43 (accessed 30 October 2021).UK Government (2020): New Decade New Approach, p.9 (accessed 1 November 2021).

[80] Ibid, p.93.

[81] Northern Ireland Commissioner for Children and Young People (2018): Still Waiting? A rights-based review if mental health and support services for children and young people in Northern Ireland, p.14, Belfast: NICCY.

There is evidence to suggest that children and young people with disabilities have difficulty accessing the legal system and that persons appointed to represent disabled children in court are not always aware of the issues affecting disabled children or adults relating to their access to the justice system[82].

There is limited data through which to monitor progress with respect to d/Deaf and disabled children and therefore there continues to be an absence of indicators through which to monitor progress. There are challenges associated with ensuring that d/Deaf and disabled children have the right to express their views on matters which affect them.

The Northern Ireland NGO Stakeholder Report (2020)[83], to inform the UN Committee on the Rights of the Child ‘s consideration of a list of issues, documents historic shortfalls with respect to human rights model of disability and the absence of data or monitoring mechanisms to assist the development and evaluation of policy.

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[82] Northwest Forum of People with Disabilities Casework (2018). A deaf child with communication issues was not engaged with by the social worker appointed to represent the child’s interests in the court system on the grounds that that it would be too difficult and expensive to provide a sign language interpreter to ascertain the child’s views. The Forum made representation on behalf of the child that with some effort and minimal resources the child’s views could be ascertained as to the wishes of the child and the allegations of physical abuse.

[83] Children’s Law Centre (2020): NI NGO Stakeholder Report to Inform the UN Committee on the Rights of the Child: List of Issues Prior to Reporting, p.18 (accessed 20 October 2021).

The report notes a significant lack of data relating to the experience of d/Deaf and disabled children and young people who require sign language. There are challenges associated with ensuring that d/Deaf and disabled children have the right to express their views on matters which affect them. There is a lack of statistics and evidence regarding the lived experience of d/Deaf and disabled children available to policymakers.

The Rights of d/Deaf and Disabled Women

The rights of d/Deaf women and girls have yet to be mainstreamed into disability and gender related policies by the Executive in closed consultation with d/Deaf disabled women and girls and the organisations which represent them.

Evidence suggests that d/Deaf and disabled women are two times more likely to suffer physical abuse from an intimate partner than nondisabled women[84]. d/Deaf and disabled women who experience domestic abuse face compound oppressions[85].

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[84] Slayter, E. (2009): Intimate partner violence against women with disabilities: implications for disability service case management practice. Journal of Aggression, Maltreatment and Trauma 2009, 18:182–199. doi:10.1080/ 10926770802675668 reference in Breckenridge et al. BMC Pregnancy and Childbirth 2014, 14:234. Available at http://www.biomedcentral.com/1471-2393/14/234 (accessed 30 October 2021)

[85] Nixon, J. (2009): Domestic violence and women with disabilities: locating the issue on the periphery of social movements. Disability and Society 2009, 24:77–89.

Women's Aid Northern Ireland report that 41% of women in refuges and 41% of women accessing outreach services have a disability[86]. There is a lack of specialist services for deaf and deaf and disabled people experiencing domestic violence and many services are inaccessible[87]. There are barriers to d/Deaf and disabled women regarding access to health services including maternity services, cervical and breast screening services, and sexual and reproductive healthcare services[88]. The current Department of Health Maternity Strategy[89] makes little reference to the experience of disabled women. Health screenings such as cervical examinations and mammograms can be especially difficult with no support, information, accessible equipment, or transport[90].

Monitoring and Evaluation

There is limited evidence of the incorporation or implementation of the UNCRPD across Executive Departments, legislation, policies, and programmes.

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[86] Women's Aid Federation NI (2020): Annual Report 2019-2020 (accessed 2 November 2021).

[87] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.118 (accessed 10 October 2021).

[88] Ibid, p.117.

[89] DoH (2012): A strategy for maternity care in Northern Ireland 2012 – 2018 (accessed 29 October 2021).

[90] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.118 (accessed 10 October 2021).

There are significant gaps in the collection of disability statistics and limited availability of disaggregated data. There is no official collection of appropriate data related to the lived experience of deaf and deaf and disabled people or the impact of changes in legislation with respect to disability in Northern Ireland. This is further compounded by the absence of a clear agreed definition of disability[91].

Conclusions

This research has provided an overview of the current position regarding progress with respect to the obligations and provisions in the UNCRPD in NI. In so doing it has taken explicit account of both the UNCRPD articles and the subsequent observations made by the UN Committee in 2017. Ultimately, the research has identified a range of shortfalls in delivery in Northern Ireland relative to the UNCRPD and has outlined recommendations for change. This report provides information to IMNI to assist with the independent monitoring role with respect to the UNCRPD.

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[91] DfC (2020): Disability Expert Advisory Panel Report and Recommendations, p.25.

Progress with respect to the Disability Strategy will be core to the realisation of UNCRPD rights and protections. At the time of writing, there are concerns that the cross-departmental aspects of the strategy combined with reductions in Departmental budgets could slow progress. Covid-19 has brought the importance of the UNCRPD to the fore, emphasising the need to protect the lives of d/Deaf and disabled people and to ensure equal recognition before the law. The extent of abuse uncovered in Muckamore Abbey Hospital illustrates the urgent need to ensure that the rights of d/Deaf and disabled people are upheld.

This report is the third in a series of reports on progress with respect to the UNCRPD which have called for similar protections for d/Deaf and disabled people in NI to those which d/Deaf and disabled people in the rest of the UK enjoy.

Welfare reform continues to have significant adverse impacts on the right of d/Deaf and disabled people to an adequate standard of living. The mitigations package agreed by the Executive and the actions taken to close the gaps within the package are welcome and provide some protections. However, the mitigations do not address all of the adverse impacts of welfare reform.

The lack of accessibility continues to pose significant challenges to independent living. It is hoped that this report will act both as a source of evidence and a stimulus for change.

About us

Disability Action is a Northern Ireland-based pan-disability organisation. We have worked with d/Deaf and disabled people, Disabled People's Organisations (DPO's), and Civic Society Organisations (CSOs) across the region in the development of this report. This report has been compiled by d/Deaf and disabled people.

Definitions

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 UN Convention on the Rights of People with Disabilities[92] (UNCRPD). 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 UNCRPD[93]. This approach follows that which was adopted within the Disability Strategy Expert Advisory Panel Report and Recommendations[94].

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[92] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly (accessed 4 November 2021).

[93] Ibid.

[94] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.5 (accessed 10 October 2021).

This report has been developed utilising the human rights model of disability, taking account of the social model of disability[95]. The human rights model focuses on the inherent dignity of the human being and places the individual centre stage in all decisions. Most importantly, it recognises the role which society plays in disability[96]. The social model of disability asserts that disability is a form of oppression and socially created disadvantage and marginalisation of people on the basis of disability or impairment. Disability is therefore considered as a socially produced injustice which is possible to challenge and address through social change[97].

Both models recognise that the challenges of disability are societal factors which are external to the individual. The human rights model both builds on and complements the social model.

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[95] Oliver, M. (1981): A new model of the social work role in relation to disability, pp.19-32 (accessed 1 January 2022).

[96] Quinn, G. and Degener, T. (2002): The moral authority for change: human rights values and the worldwide process of disability reform, Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability, pp.9-18 New York, Geneva: United Nations.

[97] Lawson, A. and Beckett, A.E. (2020): The social and human rights models of disability: towards a complementarity thesis, *The International Journal of Human Rights*, *25* (2), pp.348-379.

Both models are valuable tools towards achieving equality, participation, inclusion, quality of life and dignity for d/Deaf and disabled people. For some purposes, including the monitoring of the State party's efforts to implement the UNCRPD[98], the human rights model is more appropriate. The social model plays an essential role in the identification of barriers and the development of appropriate solutions[99].

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[98] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 (accessed 4 November 2021).

[99] Lawson, A. and Beckett, A.E. (2020): The social and human rights models of disability: towards a complementarity thesis. *The International Journal of Human Rights*, *25* (2), pp.348-379.

Introduction

This report is a review of the work on the United Nations Convention (‘the Convention’) on the Rights of Persons with Disabilities (UNCRPD) undertaken within NI. The UNCRPD is a global international human rights treaty setting out the human rights of d/Deaf and disabled people. This report is an assessment of the progress has been made by the Northern Ireland Executive with respect to the implementation of the United Nations Convention (“the Convention”) on the Rights of Persons with Disabilities since the last periodic review by the CRPD Committee in 2017 which made a total of 88 recommendations as a benchmark to demonstrate the level of progress over the last 4 years.

The review was undertaken by Disability Action on behalf of the Equality Commission for Northern Ireland. The Equality Commission for Northern Ireland, as part of the Independent Mechanism for Northern Ireland,[100] has contracted research to develop a series of expert papers to set out evidence of any substantive shortfalls of public policies and programme delivery set against the key requirements of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)[101] which the UK Government signed up to in 2009.

This report is the third in a series of reports (reports were also published in 2012 and 2014) examining how well the Northern Ireland Executive is progressing the implementation of the UNCRPD.[102] [103]

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[100] The Independent Mechanism for Northern Ireland (IMNI), the Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission have been jointly designated as the focal point by the Northern Ireland Executive to promote, protect and monitor the implementation of the United Nation Convention on the Rights of Persons with Disabilities. Together with the Equality and Human Rights Commission in England and Wales and the Human Rights Commission in Scotland they are also part of the United Kingdom Mechanism (UKIM) are required to report progress to the UN Committee on the Rights of Persons with Disabilities on how well each of the devolved nations and the UK Government as a whole, are progressing with the with implementation of the UNCRPD.

[101] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly (accessed 4 November 2021).

[102] Harper, C., McClenahan, S., Byrne, B. and Russell, H. (2012): Disability Programmes and Policies how does Northern Ireland measure up?.

[103] Byrne B., Harper, C., Irvine R. S., Russell H. and Fitzpatrick, B. (2014): UNCRPD: Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD, pp.56-57 (accessed 23 October 2021).

This research is partly an update on both reports, with its main focus assessing how the Northern Ireland Executive has responded to the examination by the UNCRPD Committee and implemented the Convention in Northern Ireland based on the concluding observations and recommendations made by the UNCRPD Committee in 2017[104]. This report will highlight the gaps in public policy and programmes in Northern Ireland for the attention of the UN Committee during their scheduled examination of the progress by Great Britain and Northern Ireland to implement the UNCRPD.

In particular, it will inform:

- potential topics to be raised to the attention of the UN Committee and subsequently the list of issues which are estimated to be adopted in August 2022;
- submissions to the UN Committee, by the UK Independent Mechanism to assist in the examination of the UK State Party; engagements with the NI Executive, Departments and Stakeholders in NI regarding the advancement of the Convention rights and equality for deaf and disabled people in NI.

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[104] 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/ (accessed 3 November 2021).

This report will inform the Independent Mechanism's submission regarding the review of the next UK State Party report by the UNCRPD in 2023.

Background and Context

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)[105] is an international agreement drawn up by States with the involvement of d/Deaf and disabled people which affirms that d/Deaf and disabled people have the same rights as non-disabled people. The UNCRPD was drafted and written by d/Deaf and disabled people. The Convention represents a major step forward in recognising the rights of d/Deaf and disabled people to be treated as full and equal citizens and promotes the social model of disability. To date the UNCRPD has influenced significant reforms worldwide in the areas of legal capacity, personal decision-making, and independent living arrangements[106]. The implementation of the UNCRPD[107] has been slow within NI.

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[105] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly (accessed 4 November 2021).

[106] McNamara, D. (2020): Building a Collaborative Approach to Policing in an Age of Disability Human Rights Law, The Journal of Psychiatric and Mental Health Nursing, 31 January 2020, p.1 (accessed 20 November 2021).

[107] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly (accessed 4 November 2021).

The Convention represents d/Deaf and disabled people as rights holders and human beings and adopts a rights-based approach towards issues facing d/Deaf and disabled people.

Article 3 of The Convention[108] embeds 8 key principles:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- non-discrimination;
- full and effective participation and inclusion in society;
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- equality of opportunity;
- accessibility;
- equality between men and women;
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

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[108] Ibid.

The Convention covers a wide range of areas including:

- access to decision making;
- health;
- education;
- employment;
- access to justice;
- personal security;
- independent living;
- access to information.

Governance and Monitoring

The implementation of the Convention by each State is monitored by the UN Committee on the Rights of Persons with Disabilities. The Committee is made up of 18 independent human rights experts who are d/Deaf and disabled people and who have been nominated by States that have signed up to the UNCRPD. Subscribing State Parties are required to submit reports to the Committee on the implementation of the Convention. The 'State Report' set out the laws and policies put in place to implement the UNCRPD and their impact on the rights of d/Deaf and disabled people.[109]

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[109] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly.

An Optional Protocol to the Convention requires subscribing State Parties to recognise the competence of the Committee to receive and consider communications from individuals and organisations subject to its jurisdiction, who claim to be victims of a violation of their rights by that State Party. If the Committee receives reliable information indicating 'grave or systematic violations by a State Party of rights set forth in the Convention', it can undertake inquiries into that State Party and make recommendations for action[110]. There is no enforcement mechanism.

Under Article 33 (2) of the UNCRPD, State Parties are tasked with designating a framework, including one or more independent mechanisms, as appropriate, to 'promote, protect and monitor' the implementation of the Convention[111]. In 2009, the UK Government designated the Equality and Human Rights Commission (EHRC), the Equality Commission Northern Ireland, the Northern Ireland Human Rights Commission (NIHRC) and the Scottish Human Rights Commission (SHRC) as the UK Independent Mechanism. The Equality Commission Northern Ireland and the Northern Ireland Human Rights Commission are referred to as the Independent Mechanism for NI (IMNI).

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[110] Ibid, Articles 1-6 (accessed 4 November 2021).

[111] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 3.3 (accessed 4 November 2021).

The commencement of the UNCRPD marked an important milestone in the long and ongoing struggle for disability rights[112]. However, ratification of the treaty does not in itself change human rights practices concerning d/Deaf and disabled people[113]. Rather, the treaty has the potential to act as framework for law and policy reforms. The UNCRPD is a product of collaboration and negotiation between State delegations, expert bodies, d/Deaf and disabled people, and Disabled People's Organisations (DPOs)[114].

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[112] Kayess, R. and French, P. (2008): Out of the Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities, Human Rights Law Review, 8 (1), 1-34, p.1 (accessed 6 December 2021).

[113] Kanter, A. (2014): The Development of Disability Rights Under International Law: From Charity to Human Rights, p.23, Routledge.

[114] Paragraph 11 of the UNCRPD General comment No. 7 refers to some distinguishing characteristics of DPOs:

'The Committee considers that organizations of persons with disabilities should be rooted, committed to and fully respect the principles and rights recognized in the Convention. They 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. Organizations of women with disabilities, children with disabilities and persons living with HIV/AIDS are organizations of persons with disabilities under the Convention. Organizations of persons with disabilities have certain characteristic aspects, including the fact that:

(a) they are established predominantly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities and should be generally recognized as such;

(b) they employ, are represented by, entrust or specifically nominate/appoint persons with disabilities themselves;

(c) they are not affiliated, in the majority of cases, to any political party and are independent from public authorities and any other non-governmental organizations of which they might be part/members of;

(d) they may represent one or more constituencies based on actual or perceived impairment or can be open to membership of all persons with disabilities;

The Convention is intended to enable the lived experience of d/Deaf and disabled people to inform policy, legislation, and practice.

In 2016 the UK was investigated under the Optional Protocol of the UNCRPD which the UK ratified in 2009. The Committee on the Rights of Persons with Disabilities concluded that there were "grave or systemic violations" of rights[115] with respect to the impact of welfare reform, citing the eligibility criteria for Personal Independence Payment (PIP) and social care, the closing of the Independent Living Fund, and changes to Housing Benefit as having a disproportionate negative impact on the rights of d/Deaf and disabled people. The UK Government published a response[116] which strongly disagreed with the findings.

(e) they represent groups of persons with disabilities reflecting the diversity of their backgrounds (in terms of, for example, sex, gender, race, age, or migrant or refugee status). They can include constituencies based on transversal identities (for example, children, women or indigenous people with disabilities) and comprise members with various impairments;
(f) they can be local, national, regional or international in scope;
(g) they can operate as individual organizations, coalitions or cross-disability or umbrella organizations of persons with disabilities, seeking to provide a collaborative and coordinated voice for persons with disabilities in their interactions with, among others, public authorities, international organisations and private entities'.

[115] UN Committee on Rights of Persons with Disabilities (2016): 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: Committee on the Rights of Persons with Disabilities: report of the Committee, CRPD/C/15/R.2/Rev.1 Geneva: UN, 7 October 2016, paragraph 5.

[116] UK Government (2019): The United Kingdom of Great Britain and Northern Ireland's 2019 response to select concluding observations of the United Nations Committee on the Rights of Persons with Disabilities: Response to recommendation in paragraph 7, London: HMSO (accessed 6 December 2021).

The Committee on the Rights of Persons with Disabilities examined the UK'S initial report on implementation of the CRPD in 2017. The Committee were highly critical, concluding that little progress had been made. The 'Concluding Observations' listed the main concerns about disabled people's human rights in the UK and made 88 recommendations for action by the UK Government and the devolved governments of Wales, Scotland and Northern Ireland. In September 2018 the UK Government issued a response to select concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, specifically the recommendation set out in paragraph 74 of the UNCRPD concluding observations.[117]

The UN Committee has asked the UK Government to:

- implement the recommendations, sharing them with all relevant government departments, local authorities, the media, and other relevant groups;
- share the conclusions widely among d/Deaf and disabled people's organisations, other disability groups, d/Deaf and disabled people, and their families, in national and minority languages and accessible formats;

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[117] UK Government (2018): Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland: initial government response.

- provide an update within 12 months on the actions it has taken on three areas: living independently and being included in the community; work and employment; and an adequate standard of living and social protection;
- work closely with d/Deaf and disabled people's organisations to follow-up on the recommendations in the UN Committee's inquiry report and provide updates every 12 months until the next review of the UK;
- submit its next progress report by 8 July 2023, and include information on how it has implemented the Committee's recommendations;
- involve d/Deaf and disabled people's organisations when it prepares its next report for the UN Committee and provide funding to support their involvement.

The UN Committee also raised concerns regarding barriers to d/Deaf and disabled people's rights in education, access to justice, participation in public life, and healthcare. The UK Independent Mechanism (UKIM), along with d/Deaf and disabled people's organisations, have urged progress on the implementation of all the UN Committee's recommendations to strengthen the protection of d/Deaf and disabled people's rights in the UK[118].

The UN Committee has set out its main concerns regarding the UK's progress on the implementation of the Convention and made recommendations for improvement. The UN Committee were concerned that not enough is being done to apply the Convention consistently across the UK, to involve d/Deaf and disabled people in decisions that affect their lives, and to put the human rights model of disability into practice.

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[118] UKIM (2018): Government's response to the UN report on the Convention on the Rights of Persons with Disabilities: Briefing by the UK Independent Mechanism, Westminster Hall Debate 20 June 2018, p.1 (accessed 14 October 2021).

The human rights model of disability focuses on the dignity of d/Deaf and disabled people, views d/Deaf and disabled people as part of human diversity and acknowledges that d/Deaf and disabled people have human rights and recognises that people are disabled not by an impairment, but by barriers in the society and environment they live in, such as negative attitudes and inaccessible public spaces.

The UN Committee recommended that the UK should:

- incorporate the Convention into UK law, so that it can be enforced in UK courts;
- ensure that the human rights model of disability is protected by law and informs policies affecting d/Deaf and disabled people across the UK;
- carry out a full review of the UK’s laws and policies to bring them into line with the Convention;
- develop a plan of action to abolish any laws, regulations, customs, and practices that discriminate against d/Deaf and disabled people;
- this plan should be measurable and fully funded;
- stop d/Deaf and disabled people being negatively affected by the UK leaving the European Union (EU);

- collect information and set out a plan to improve d/Deaf and disabled people's living conditions;
- financially support d/Deaf and disabled people's organisations and ensure that d/Deaf and disabled people are fully involved in developing and implementing all policies and laws that affect their lives. These plans should be measurable, properly funded and regularly monitored[119].

Moving forward, the UK Government and devolved governments are required to put in place a National Framework to promote, protect and monitor the implementation of the UNCRPD. In Northern Ireland the Department for Communities is responsible for this.

The UK Government established an Inter-Ministerial Group on Disability and Society to drive forward co-ordinated action across Government on the 22 May 2018[120]. The Group has the goal of bringing Departments together to jointly tackle barriers to the participation of disabled people's full participation in public life and to drive through progress against the implementation of the Convention.

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[119] 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, paragraphs 7 and 9 (accessed 26 November).

[120] UKIM (2010): Overview of key concerns about social security reforms and protecting disability rights in the United Kingdom (accessed 20 November 2021).

UKIM has sought clarification as to whether the Inter-Ministerial Group will take forward the UN Committee's recommendations, the manner in which it relates to the devolved administrations and the manner in which it will engage with DPOs[121]. The Northern Ireland Executive are in the process of developing a disability strategy involving DPOs and disabled people in the development of the strategy[122]. There remain challenges in the full incorporation of the UNCRPD within Northern Ireland (NI).

The overall aim of the UNCRPD is to establish d/Deaf and disabled people as rights holders[123]. If properly incorporated within domestic law in NI, the UNCRPD would provide an extensive network of rights which would protect and empower disabled people[124]. Perhaps most importantly the UNCRPD embodies a mandate for d/Deaf and disabled people and DPOs to be full and active participants in the development of law and policy which impacts upon their lives. It should be noted that the strength within this aspect of the UNCRPD has yet to be realised within the NI context.

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[121] UKIM (2018): Westminster Hall Debate (accessed 25 January 2022).

[122] DfC (ND): Disability Strategy co-design group - terms of reference (accessed 26 November).

[123] Degener, T. (2016): Disability in a human rights context, Laws 5: 35 (accessed 26 November),

[124] Harpur, P. (2012): Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. *Disability and Society*, 27: 1–14.

The Northern Ireland Context

> "*Departments and Public Authorities ignore these human rights obligations with impunity. Enforcement is non-existent and the oversight bodies developed to ensure enforcement of human rights standards and protections are either too reluctant or incompetent to make any real change to the ableist culture which dominates decision making".*
>
> **Male carer, aged 40-44**

Following the Belfast / Good Friday agreement in 1998[125], the UK government devolved legislative powers to the Northern Ireland Assembly (the Assembly). The Assembly has power over devolved or transferred matters which include agriculture, education, housing, employment, health and social care, social security and policing and justice matters. Equal opportunities and discrimination are 'transferred matters' for the Northern Ireland Assembly, under the Northern Ireland Act 1998[126], but not for the Scottish Parliament or the National Assembly for Wales.

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[125] The Good Friday Agreement (1998).

[126] Northern Ireland Act (1998).

The Northern Ireland Assembly and Executive has experienced instability during the reporting period. The collapse of the institutions in 2016 led to a legislative hiatus which further complicated the challenges within the region associated with the legacy of the recent conflict. NI as a region faces significant challenges due to underfunding and the complexity associated with addressing gaps and deficits in equality law in the absence of agreement on a Single Equality. The institutions became operational again in early 2020 but have faced significant challenges in the context of the ongoing Covid-19 crisis and the implications of Brexit.

The New Decade New Approach[127] (NDNA) agreement which accompanied the reinstatement of the institutions requested that the Programme for Government is underpinned by a Disability Strategy[128]. Work commenced on the Disability Strategy in September 2020 with a target date for publication of December 2021. This deadline has passed at the time of writing.

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[127] UK Government (2020): New Decade New Approach, paragraph 4.6, p.27.

[128] Ibid.

The approach to developing the new strategy involved the creation of the Disability Strategy Expert Advisory Panel[129]. The Panel published their findings and recommendations on 5 March 2021[130] and recommended that the proposed disability strategy addressed the following requirements:

- 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.[131]

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[129] DfC (ND): Disability Strategy expert advisory panel - terms of reference.

[130] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.1 (accessed 10 October 2021).

[131] Ibid, p.4.

There have been some positive developments including the establishment by IMNI of a Disability Forum[132] which has been established as a mechanism through which d/Deaf and disabled people can work together with the Independent Mechanism to see to secure the implementation of the UNCRPD. Recent progress towards a New Disability Strategy is also welcome.

The report of the Disability Strategy Expert Advisory Panel Report has concluded that the devolved administration in NI has not taken adequate steps to progress the implementation of the Convention[133]. The panel noted that the Convention is not directly incorporated into domestic law and that the NI Executive has not given the Convention due consideration in the development of policy and legislation[134] [135].

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[132] ECNI (2021): First meeting of IMNI Disability Forum to work on UNCRPD implementation (accessed 26 November 2021).
IMNI Disability Stakeholder Forum, is a new body which will work towards the implementation in Northern Ireland of the UN Convention on the Rights of People with Disabilities (UNCRPD). The Forum at present involves 11 people from representative organisations and individuals with disabilities, alongside the Equality Commission for NI and the NI Human Rights Commission, acting together as IMNI, the Independent Mechanism in Northern Ireland. IMNI exists to promote, protect and monitor implementation here of the UNCRPD.

[133] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.12 (accessed 10 October 2021).

[134] Ibid, p.12-14.

[135] Professor Brice Dickson has referred to the power of the Northern Ireland Assembly to incorporate international human rights conventions being overlooked. See: Dickson, B. (2021): Implications for the Protection of Human Rights in a United Ireland', *Irish Studies in International Affairs*, 2021, Vol. 32, No. 2, Analysing and Researching Ireland, North and South (2021), pp. 589-610 at p.594.

The Chief Commissioner of the Equality Commission for Northern Ireland has stated that lack of progress to close the gaps in legal protections between equality law in Northern Ireland and Great Britain has positioned the region in the "dark ages" with respect to equality to such an extent that there is a "serious risk of falling way behind, to not being a developed country".[136]

The Report of the Disability Strategy Expert Advisory Panel provides a framework through which to address current gaps associated with the UNCRPD[137]. At the time of writing work with respect to the development of the Disability Strategy remained ongoing. There are concerns regarding the potential for the Strategy to be delivered within the current mandate due to the recent political crisis triggered by the resignation of the First Minister, Paul Givan MLA, on 3 February 2022[138].

Although progress with respect to advancing the preparation of a Disability Strategy should be acknowledged, the extent to which the recommendations of the Expert Panel and the Co-Design Group are to be reflected in the final Strategy remains to be seen.

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[136] The Irish Times (2021): Northern Ireland 'in dark ages' in terms of equality laws, 20 October 2021 (accessed 5 November 2021).

[137] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.12-14 (accessed 10 October 2021).

[138] Irish Times (2022): Paul Givan resigns as First Minister of Northern Ireland in DUP protocol protest (accessed 19 February 2022).

At the time of writing there is no coherent delivery plan to address the requirements of the Convention within the NI context. It is not clear whether the new Disability Strategy 2022-2027 will be delivered against the framework of the UNCRPD or considered as a response to the concluding observations and recommendations of the UNCRPD Committee. IMNI has recommended that any future disability strategy should be considered as the framework for implementing the Convention to facilitate reporting to the UNCRPD Committee.

Additional concerns relate to barriers to cross-Departmental working and budget reductions[139] which present significant impediments to agreement of the Strategy before the end of the current mandate. Although lead responsibility for the Disability Strategy is located within the Department for Communities, realisation of the strategy is dependent on cross-Departmental working, as the required measures extend across the remits of all Departments.

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[139] DoF (2021): Budget Consultation (accessed 29 December 2021).

The main focus of the Good Friday Agreement was to develop a political structure that bridged community divisions and created a framework for parties to work together. An unforeseen challenge arising from the political structures was the extent to which party differences would impact on the capacity of the Executive to deliver. There continues to be an absence of collective policy ownership within the Executive[140].

The NI Executive faces significant funding pressures. The Budget Consultation published by the Department of Finance in 2021 proposed that all Departments take a reduction in their baseline budgets to divert resources to health and social care[141].

At the time of writing there has been no formal response to the UNCRPD Concluding Comments from the NI Executive. Progress towards the realisation of rights of d/Deaf and disabled people has been slow. Moving forward it is essential that the rights of d/Deaf and disabled people receive adequate protection and are advanced.

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[140] Pivotal (2020): Good Government in Northern Ireland, p.2 (accessed 25 January 2022).

[141] DoF (2021): Budget Consultation, p.2 (accessed 29 December 2021).

Brexit continues to present challenges to the region with respect to instability of the institutions, governance, and operational challenges. While there is a commitment towards the non-diminution of rights in the context of Brexit[142], the resulting instability and disruption emerging from Brexit have had negative impact on d/Deaf and disabled people the full extent of which is not yet fully understood. The EU has been pivotal in enhancing domestic equality law for d/Deaf and disabled people in the UK.[143] For example, the Equal Treatment Directive on Employment and Occupation, referenced in annex 1 of the Northern Ireland Protocol[144], contains provisions regarding the elimination of discrimination against disabled people, positive action measures on the integration of disabled people in employment and the requirement to provide reasonable adjustments and accommodations[145].

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[142] NIO (2020): Explainer: UK Government commitment to no diminution of rights, safeguards and equality of opportunity in NI (accessed 3 January 2020).

[143] For example, the Employment Equality Framework Directive 2000 removed the exemption for small companies to employ disabled people which went beyond the UK's disability equality legislation.

[144] UK Government (ND): UK Government commitment to "no diminution of rights, safeguards and equality of opportunity" in Northern Ireland: What does it mean and how will it be implemented?, paragraphs 6 - 7 (accessed 29 November 2021).

[145] The Equality Framework Directive 2000/78/EC – General Framework for Equality Treatment in Employment and Occupation (accessed 1 October 2021).

Brexit continues to put human rights protections at risk. In the UK-EU Joint Report, the UK committed “to ensuring that no diminution of rights is caused by its departure from the EU, including in the area of protection against forms of discrimination enshrined in EU law”. It also committed to “facilitating the related work of the institutions and bodies, established by the 1998 Agreement, in upholding human rights and equality standards” in December 2017[146].

This commitment is reflected within Article 2 “Rights of Individuals” within the Northern Ireland Protocol to the Withdrawal Agreement[147], binding to the UK Government and Parliament and the Northern Ireland Executive and Assembly as a matter of international law. International obligations under the Withdrawal Agreement became UK domestic law when parliament passed the European Union (Withdrawal Agreement) Act 2020 in January 2020.

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[146] Prime Minister’s Office (December 2017): Joint report on progress during phase 1 of negotiations under Article 50 TEU on the UK’s orderly withdrawal from the EU, paragraph 53. p.8, London: HMSO (accessed 29 November 2021).

[147] DfEEU (2018): New Protocol on Ireland/Northern Ireland and Political Declaration: Article 2 Rights of Individuals, London: HMSO (accessed 29 November 2021).

Schedule 3 of the 2020 Act confers new functions on the Equality Commission for Northern Ireland (ECNI) and the Northern Ireland Human Rights Commission (NIHRC), to enable each to act as part of the 'Dedicated Mechanism' (DM), to monitor, advise, report on and enforce the UK's adherence to its commitment that there will be no diminution of rights, safeguards or equality of opportunity in Northern Ireland covered by the relevant chapter of the Belfast Agreement[148] as a result of the UK's exit from the EU. This came into force at the end of the transition period, 31 December 2020[149].

In July 2021, the UK Government published a command paper[150] which sets out proposals to replace the Northern Ireland Protocol. The EU responded in October 2021 with proposals[151]. At the time of writing, the UK and the EU continue to be in extensive negotiations. The UK has indicated that the absence of progress could result in unilateral action by the UK of the protocol's safeguarding clause, Article 16[152]. In this scenario, the EU is likely to respond with legal action and eventually possible retaliatory measures.

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[148] Prime Minister's Office (2017): Joint report on progress during phase 1 of negotiations under Article 50 TEU on the UK's orderly withdrawal from the EU.

[149] NIHRC (2020): New human rights & equality oversight roles begin.

[150] Cabinet Office and Northern Ireland Office (2021): Northern Ireland Protocol: The way forward, 21 July 2021 (accessed 11 October 2021).

[151] European Commission (2021): Protocol on Ireland and Northern Ireland, 2021

[152] UK Government (2019): The Protocol on Ireland/Northern Ireland, Article 16.

Although both the UK Government and the EU Commission have recognised the importance of engagement with civic society there has been little or no evidence of this being put into practice. There has been no formal engagement by the State party with d/Deaf and disabled people and the wider disability sector as to the potential impact of Brexit, including the recent introduction of the Northern Ireland protocol. However, in May 2021 the Northern Ireland Civic Working Group on the Protocol (NICWGP)[153] was established in recognition of the significant impact that Brexit and the Northern Ireland Protocol has had and will likely continue to have on Northern Ireland.

Members of the Working Group represent sectors of the community across Northern Ireland society. Currently, the constitution of the Working Group represents the following sectors and communities: Children and Young People; Churches; Community Relations; Cross-Border Cooperation; Environmental Protection; Human Rights; LGBTQI; Migrant Communities; Peacebuilding; d/Deaf and Disabled People;

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[153] The NICWP is chaired by Professor Katie Hayward, Professor of Political Sociology, Queens University Belfast, and Senior Fellow of the UK in a Changing Europe Think Tank. Professor Hayward is an internationally recognised expert on Brexit and Northern Ireland, appointed to the Technical Expert Panel of the UK Governments Alternative Arrangements Advisory Group on Brexit (2019).

Rural Communities; Trade Unions; Women; Victims and Survivors; and Voluntary Associations.[154]

The NICWP serves three primary functions:

- to enable direct and constructive communication between civic actors across sectors and communities of Northern Ireland society and those responsible for decision-making with respect to the Protocol, both directly and indirectly at UK and EU level;
- to improve international influencers and decision-makers' understanding of the societal impact of the Protocol/Brexit in a way that is independent from political and official mechanisms;
- to improve understanding and communication about the Protocol 'on the ground' across all sectors and communities.[155]

The NICWP has had meetings and discussions with a wide range of stakeholders including the EU Task Force, the Northern Ireland Office (NIO) and the Cabinet Office as well as individual representation from EU and non-EU states such as New Zealand, Australia, and the United States.

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[154] The Northwest Forum of People with Disabilities and Disability Action represent the disability sector in Northern Ireland on the NICWP.

[155] Working Group Northern Ireland Protocol (May 2021) agreed Terms of Reference. Unpublished hard copy (accessed 20 September 2021).

Key issues of concern to d/Deaf and disabled people that have been highlighted include:

- the future loss of rights because of the non-realignment of domestic equality law with future positive developments in European equality legislation. For example, the European Accessibility Act (2018) on the accessibility requirements of products and services yet to be incorporated into EU law;
- the loss of European funding for existing state employment programmes and other European initiatives;
- cross-border travel as it impacts on disabled people e.g. the bureaucracy and costs related to the use of assistance dogs;[156]

- the potential rising costs of goods and services as a result of Brexit. Some experts have argued that the Northern Ireland economy will eventually benefit from having unfettered access to the Great Britain (GB) market while still being part of the EU single market. This becomes less likely to the extent that persistent frictions between GB and Northern Ireland (in respect of trade) will lead to higher costs that will likely impact on low-income groups such as d/Deaf and disabled people.[157]

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[156] Inclusion Mobility Transport Advisory Committee (2021): Post Brexit Travel with Assistance Dogs Update (Accessed 23 September 2021).

[157] Birnie, E. and Brownlow, G. (2021): How is Brexit affecting Northern Ireland's Economy? (accessed 29 November 2021).

There are significant challenges facing the UK with respect to maintaining pace with European equality law in the future.[158] The EU is itself a party to the UNCRPD. Under EU law, international treaties to which the EU is party have a different status than they do under UK law. For example, EU law must be interpreted consistently with the UNCRPD. UKIM has maintained therefore, that in order to ensure that there is no regression from Convention rights, that the Convention is incorporated into UK law, and NI law[159].

At the time of writing the Northern Ireland Executive and Assembly had entered a political crisis due to the resignation of First Minister Paul Givan. The resignation was made in the context of the DUP's opposition to post-Brexit checks on food and farm products that were brought as part of the Northern Ireland protocol between the UK and EU[160]. The Executive and Assembly now have limited decision-making powers. Although Ministers will remain in place, there is no process for the Executive to meet[161].

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[158] Whitmore, C. (2020): How Brexit will Affect Disabled People's Lives and Rights.

[159] Although the UK Government has repeatedly reiterated its commitment to making the CRPD a reality for all disabled people in the UK and has claimed to be a global leader in disability rights, it has not incorporated CRPD rights into domestic law, or taken steps to implement disabled people's rights systematically across the UK. UKIM (2018): Progress on disability rights in the UK: UK Independent Mechanism update report to the UN Committee on the Rights of Persons with Disabilities, p10.

[160] UK Government (2018): Protocol on Ireland/Northern Ireland.

[161] The Guardian (2022): Why Paul Givan quit – and what it means for Stormont.

Methodology and Approach

Disability Action wish to ensure that this report centres upon what d/Deaf and disabled people have told us with respect to their experiences, the issues that they raise with us every day and those that are having the biggest impact on deaf and disabled people attaining their rights in NI. This report employs a human rights-based, mixed methodology and employs an analytical framework which considers:

- structure i.e., commitments to UNCRPD rights made in the governance framework of NI e.g., legislation and policies;
- process i.e., the implementation of such commitments;
- outcome i.e., the real-life results for d/Deaf and disabled people arising from these commitments.

Desktop research was carried out into relevant programmes and policies. Data collection was undertaken during November and December 2021. This involved the collection and analysis of survey data from 84 individuals and 3 research focus groups[162] which were attended by a total 143 d/Deaf and Disabled people. Survey data was collected from 9 Government Departments. Individual interview discussions were undertaken six political parties.[163]

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[162] Undertaken remotely via Zoom.

[163] All parties were contacted to participate in the research but unfortunately some did not respond within the required timescale.

The aims of the survey and discussions were twofold. First, to assist the research team to develop a wider understanding of the specific human rights issues faced by d/Deaf and disabled people in Northern Ireland at present and how these may have changed since 2017. Secondly, to assist the research team to identify priorities, gaps, and developments relevant to the research and to inform the analysis and recommendations emerging from the project.

Language is an important aspect of both the Human Rights and Social Model of Disability because language reflects the cultural assumptions and thinking of the society. Participants in the survey were offered the option to identify as a disabled person, or a person with a long-term health condition, or both. These options were offered in the context that the survey was open to all and cognisant that there are people in society who have long term health conditions who may not identify as a disabled person. This approach also allowed disabled people to indicate if they had long-term health conditions alongside a disability. This language is in keeping with the human rights model and social model, as all participants had the opportunity to identify solely as a disabled person.

The human rights model acknowledges the importance of addressing matters of health whilst at the same time recognising that disability persists due to social exclusion and societal barriers[164]. This approach was applied to ensure consistency with respect to assessing progress regarding the implementation of the UNCRPD between this research and similar work which has been undertaken in England and the other Devolved Nations.

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[164] Quinn, G. and Degener, T. (2002): The moral authority for change: human rights values and the worldwide process of disability reform, Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability, pp.9-18 New York, Geneva: United Nations.

The Impact of the UNCRPD on the lives of d/Deaf and Disabled People in NI Findings from the survey of individuals

A survey of individuals regarding the impact of the UNCRPD on the lives of d/Deaf and disabled people was undertaken between 10 November and 20 December 2021. The survey collected qualitative and quantitative data from 84 individuals via a snowball sampling strategy in partnership with DPOs and Civic Society across the region.

- 67% (56) respondents were women and 29% were men.
- 6% (5) reported that their gender was different to that assigned at birth. 6% (5) responses were from people who identifed with the LGBTQ+ community.
- 22% (18) reported that they lived in a rural area. 41% (34) considered themselves to be living on a low income;
- 65% (54) of respondents identified as a disabled person, 45% identified as having a long-term health condition (37). 25% (21) indicated that they were a disabled person or a person with a long term health condition caring for another disabled person or person with a long term health condition. 20% (17) indicated that they were a non-disabled person caring for a disabled person or person with a long term health condition.

- 5% (4) indicated that they were a representative from a DPO, and
- 5% (4) indicated that they were a non-disabled person.

Responses highlight the very signfiicant challenges in advancing the rights of d/Deaf and disabled people within NI:

- 89% (74) of respondents felt that disabled people continue to find it difficult to find and keep a job;
- 88% (73) of respondents indicated that they believe there are negative attitudes and discrimination towards d/Deaf and disabled people in NI;
- 67% indicated that they did not believe that d/Deaf and disabled people are adequately protected against discrimination in NI;
- 82% of respondents reported that there were not enough opportunities for d/Deaf and disabled people to be involved in the planning process in response to Covid-19;
- 80% of respondents believed that there was not enough planning in place to protect d/Deaf and disabled people during the Covid-19 pandemic;
- 81% (67) of respondents believe that buildings, housing, and transport are inaccessible to d/Deaf and disabled people;
- 78% (65) of respondents did not feel that d/Deaf and disabled people have enough money to have a decent life;

- 76% (63) of respondents indicated that d/Deaf and disabled people do not have enough access to support to live independently;
- 72% (60) of respondents felt that d/Deaf and disabled people find it hard to get help and support when they have a legal problem, with 63% (52) indicating that there is not enough financial support for d/Deaf and disabled people when they are accessing justice in NI;
- 65% (54) of respondents felt that the rights of d/Deaf and disabled women were not given enough attention;
- 61% (51) of respondents felt that d/Deaf and disabled people still have problems voting in elections and taking part in politics;
- 59% (49) of respondents believe that d/Deaf and disabled children's rights are unprotected;
- 57% (47) of respondents indicated that they do not think that d/Deaf and disabled children and people are able to fully take part in education.

Qualitative data collected through the surveys provided rich evidence regarding the current experiences of d/deaf and disabled people within NI. The data crosscut all of the rights which are enshrined within the UNCRPD.

Key themes emerging from the data demonstrated:

- the regression of the rights of d/Deaf and disabled people due to the ongoing damaging impact of austerity and welfare reform on the lives of d/Deaf and disabled people;
- extensive reports of experiences of discrimination;
- the negative impact of Covid-19 on the physical and mental health of d/Deaf and disabled people, the collapse of health and social care services, increased reliance on food banks, isolation, and continuing difficulties in accessing medicine and healthcare;
- concerns regarding Do Not Resuscitate Orders (DNRs);
- barriers in accessing healthcare;
- the lack of provision of social care which is resulting in people remaining within institutions and hospitals;
- the absence of d/Deaf and disabled people within Covid-19 planning and the lack of services and measures addressing the needs and requirements of d/Deaf and disabled people;
- the lack of opportunities for independent living experienced by many d/Deaf and disabled people within the region coupled with reductions in funding;
- barriers in accessing and continuing in education;
- concerns regarding the use of restraint in education settings;

- the absence of play and social experiences for d/Deaf and disabled children;
- poor availability of changing places toilets resulting in d/Deaf and disabled people having to change on dirty toilet or bathroom floors;
- ongoing stigma associated with mental health challenges;
- the lack of access to legal redress;
- the lack of access to hate crime advocacy;
- high levels of bullying and hate crime;
- high levels of abuse and violence;
- the lack of opportunities for d/Deaf and disabled people to participate in decision making, under-representation in politics and barriers to voting;
- the need for legislation to protect the rights of d/Deaf and disabled people and enforcement measures to effect change;
- extensive evidence of experiences of employment and workplace discrimination;
- little to no access to accessible housing;
- the lack of accessible transport and barriers in access to forms of accessible transport which are currently available due to the need to pre-book, restricted timescales, or poor provision;

- challenges for people with hidden disabilities in terms of discrimination;
- the lack of voice for d/Deaf and disabled women;
- the absence of differentiated data;
- levels of frustration at the lack of progress to protect the rights of d/Deaf and disabled people.

Engagement with d/Deaf and disabled people via discussion sessions and the surveys identified the following areas as important and requiring action:

- Article 5: Equality and non-discrimination;
- Article 10: Right to Life;
- Article 11: Situations of risk and humanitarian emergencies;
- Article 12: Equal recognition before the law;
- Article 24: Education;
- Article 25: Health;
- Article 28: Adequate standard of living and social protection.

Progress with respect to the UNCRPD in NI: Findings from the Survey of Organisations and Departments

A survey of organisations, including Government Departments, was undertaken between 10 November and 20 December 2021. The survey collected qualitative and quantitative data. 9 responses were received. Responses were received from the following types of organisations and Departments:

- health;
- mental health;
- education;
- umbrella organisation;
- awareness raising;
- advocacy;
- private company;
- membership based rural organisation;
- policing.

Half of the respondents (5) indicated they were aware of legislative, policy programmes and reforms which had promoted the rights of disabled people. Examples included: health transformation; progress on hate crime; and the enforcement of equality duties.

The majority of respondents (8) indicated that they were aware of regressive measures which have negatively impacted upon disabled people, including:

- the absence of funded initiatives to address the needs of d/Deaf and disabled people;
- the response to Covid-19 leading to a decline in physical and mental health;
- the consistent absence of the voice of d/Deaf and disabled people in decision making;
- the collapse of the Assembly and Executive and subsequent lack of progress regarding the implementation of legislation to advance the rights of d/Deaf and disabled people;
- the implementation of Personal Independence Payment;
- reductions in health funding;
- poor staffing levels within health.

All organisations and Departments (9) indicated they had taken steps to advance the rights of d/Deaf and disabled people. Actions included:

- ensuring that d/Deaf and disabled people, people with hidden disabilities, and people with mental health challenges are involved in consultation processes;
- reasonable adjustments;

- developing new mental health services;
- protecting the rights of d/Deaf and disabled people under DDA in the workplace;
- promoting positive actions to employers;
- delivering consistent education on d./Deaf and disabled rights;
- reaching out to people of influence others;
- training, resources, and equipment for people with disabilities;
- developing new legislation;
- supporting young people with autism;
- seeking out the voices of rural people with disabilities to inform policy, strategy, legislation, and practice;
- including d/Deaf and disabled people in decision making.

All organisations and Departments (9) identified future priorities which they would put in place to advance the rights of d/Deaf and disabled people. Responses included:

- ensuring d/Deaf and disabled people are involved in planning
- raising awareness of statutory obligations;
- promoting and protecting mental health as a human right;
- promoting access to service as an essential aspect of equality;
- addressing injustice;

- ensuring that the organisation stays up to date on all requirements needed to protect people with disabilities;
- building partnerships to champion the rights of d/Deaf and disabled people;
- advocacy;
- advancing social inclusion strategies;
- ensuring the voices of d/Deaf and disabled people are heard.

Organisations and Departments were asked to outline the most pressing issues impacting upon d/Deaf and disabled people from their perspective. Responses included:

- support and access to justice;
- inequality of opportunity;
- growing gaps in the rights of people and their families;
- lack of data to evidence change;
- the need to promote and protect mental health;
- little or no representation of d/Deaf and disabled people in law making or enforcement bodies;
- the absence of d/Deaf and disabled people in decision making;
- accessible measures to ensure that d/Deaf and disabled people can access employment particularly during the Covid-19 crisis;

- the need to ensure that employers are aware of required actions including support, training, and equipment;
- the need to address disability hate crime;
- the voice and visibility of d/Deaf and disabled people;
- Personal Independence Payments (PIP);
- the right to work and live;
- too many people living in inappropriate settings;
- delayed discharge.

Progress with respect to the UNCRPD: Findings from the Political Representatives

A survey of political representatives was undertaken between 10 November and 20 December 2021t to help to assess progress regarding the UNCRPD in NI. The survey collected qualitative and quantitative data. 9 responses were received. 3 responses were received by Alliance MLAs, 5 from Sinn Féin MLAs and one from a political representative who preferred not to disclose party identity.

In order to address the low level of responses from MLAs, the survey was supplemented by one-to-one meetings with representatives from 6 political parties. This will be considered later in the report.

MLAs responding to the survey indicated that barriers to the full participation of d/Deaf and disabled people should be removed.

All MLAs (9) responding to the survey indicated that they believe that d/Deaf and disabled people face challenges in voting in elections and taking part in politics. Complex barriers to participation were identified by MLAs including accessibility and socio-economic challenges. Polling stations were referred to as inaccessible. MLAs highlighted the need for online voting to increase accessibility.

Many MLAs noted the positive impact of the Disabled People's Parliament which was held on 3 December 2021 commenting on the effectiveness of the event in bringing the voices of d/Deaf and disabled people to the fore.

2 MLAs who responded indicated that they were a d/Deaf and disabled person, 6 indicated that they were non-disabled, and one indicated that they were partially deaf but did not self-define as a disabled person.

7 MLAs identified legislative and policy programmes which promote the rights of d/Deaf and disabled people. These included:

- initiatives aimed at increasing participation in sport and culture, including the Active Living No Limits Action Plan and the All-Out Trekking Project;
- programmes for the employment of d/Deaf and disabled people;
- the Autism Amendment Bill;

- local actions undertaken to include d/Deaf and disabled people in decision making;
- improvements to the PIP review process whilst recognising that there remain substantial challenges to be addressed;
- welfare mitigations;
- protections against the bedroom tax;
- the development of the new Disability Strategy;
- the formal accreditation of the Executive Office by Employers for Disability NI (EFDNI);
- the introduction of Sign Language at question time;
- the consultation to increase provision for Changing Places Toilets (CPT) facilities.

1 MLA indicated that they were not aware of any positive reforms and that d/Deaf and disabled people continued to face barriers to inclusion and participation.

8 MLAs identified regressive measures which have been introduced by the UK Government and NI Assembly which have impacted upon d/Deaf and disabled people. These included:

- Brexit which has had a negative effect on protections which existed under the EU Charter of Rights and other equality protections;

- the use of Do Not Attempt Resuscitation Orders during the Covid-19 pandemic;
- the lack of inclusive information available to d/Deaf and disabled people and blind people, particularly regarding the Covid-19 regulations, restrictions, vaccinations, and health provision;
- the lack of provision for d/Deaf and disabled MLAs within the Executive and Assembly;
- challenges with respect to the PIP application process including the absence of accessibility measures such as easy read formats;
- the lack of suitable provision for children with special educational needs;
- the absence of a Disability Strategy;
- the lack of protection against direct and indirect discrimination for d/Deaf and Disabled People as a result of the absence of legislation to reflect the Equality Act 2010;
- the lack of investment in subtitles.

8 MLAs identified actions which they had taken to protect the rights of d/Deaf and disabled people. These included:

- the co-ordination of an autism group working to ensure that the long-term needs of people with autism are properly addressed within the Western Trust;

- representations with respect to independent living and benefit applications;
- lobbying for inclusive play park facilities particularly for people with autism;
- challenging PIP and changing legislation;
- supporting constituents to navigate PIP applications;
- supporting d/Deaf and Disabled people to access information and services including housing, health, Occupational Therapists, GPs, spend local cards and Covid passports;
- advancing the rights of education for children with special educational needs;
- addressing challenges in school transport for children with special educational needs;
- working to support ‘Hands that Talk’;
- participating in events hosted by Tuned In;
- working to advance the Sign Language Act;
- undertaking deaf awareness training;
- participating in the All-Party Group (APG) on Disability;
- chairing the APG on Disability;
- hosting a round table with 80 d/Deaf and disabled people;
- participating in the APG on learning disability;

- attending events on the UNCRPD;
- advancing the rights of carers;
- establishing an APG on Carers;
- joining the board of a local advocacy group;
- advancing accessibility;
- working to close the disability employment gap;
- addressing the challenges of the Common Travel Area for people with assistance dogs;
- advancing the Autism Amendment Bill;
- working for housing adaptations;
- working to ensure that vaccinations are accessible to d/Deaf and disabled people and their carers;
- improving access to hearing clinics;
- lobbying for a GCSE in Sign Language.

The Alliance Party has identified that they had taken the following actions:

- established Alliance Ability. This is a group of Alliance members with disabilities who check all policies to ensure they are inclusive. The group also develops and writes the Alliance Party policies on disability and are currently involved in developing Party policy;
- provided sign language training for members;

- encouraged members with disabilities to consider running for political office and provided mentoring support for same[165].

The Alliance Party identified the following commitments within their manifesto noting that these measures may evolve:

- sign language in schools and a sign language GCSE in NI;
- mandatory Changing Places toilets in all public buildings (new and retrofitting);
- disability and diversity awareness training for all public facing staff;
- improvements to the census to ensure data on disability is consistent and available;
- fully inclusive public transport;
- an Occupational Therapy approach to welfare assessments;
- capital investment in Special Education Schools;
- ensuring Impact Assessments asses how policy assists each section 75 group rather than addressing harm[166].

Sinn Féin identified the following actions:

- the advance of rights-based approaches by the Minister for Finance and the Minister for Communities;
- introducing changes to the PIP assessment process;

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[165] This material has been reflected directly from survey responses completed by members of the Alliance Party.

[166] Ibid.

- the continuation and broadening of welfare mitigations;
- progress with respect to the development of a Disability Strategy;
- the development of the Active Living No Limits Action Plan;
- the development of All-Out Trekking Project;
- the formal accreditation of The Executive Office by Employers for Disability NI (EFDNI) as a ‘Disability Positive’ employer;
- the achievement of Investor in People (IIP) Silver status accreditation by The Executive Office;
- the introduction of Sign language during TEO question time. Michelle O’Neill MLA, Deputy First Minister became the first Minister to use Sign Language on the floor of the Assembly;
- consultation on plans to increase provision for Changing Places Toilets (CPT) facilities and to introduce criteria for new/relevant large buildings through the building’s regulations statutory guidance;
- the commitment to incorporate the UNCRPD into domestic legislation by Junior Minister Declan Kearney at the Disabled People’s Parliament;

- the introduction of a Gender Budgeting Private Member's Bill (PMB) by Emma Sheerin MLA;[167]
- campaigns to address the profound equality implications associated with damage to wheelchairs during air travel have been taken forward by Pádraig Delargy MLA;
- exploring ways to promote increased access and support for d/Deaf and disabled people and their carers to engage in the electoral process with the Electoral Office, particularly in light of Covid 19 concerns[168].

Sinn Féin indicated that their manifesto is in development and will adopt a rights-based and equality approach to disability[169].

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[167] This will require Government Departments to identify areas of gender inequality within their department and produce an action plan and budget, disaggregated by Section 75 categories including disability, in order to identify the intersectional impacts;

[168] This material has been reflected directly from survey responses completed by Sinn Féin MLAs within the NI Assembly.

[169] Ibid.

Discussions with Political Parties

All political parties were approached to participate in discussions with respect to commitments regarding the UNCRPD. All five of the large political parties participated in discussions and People Before Profit.

The Alliance Party committed to:

- incorporating the UNCRPD into law;
- including sign language in the curriculum and the introduction of a Sign language GCSE;
- ensuring Changing Places toilets are mandatory in all public buildings (new and retrofitting);
- closing the disability employment gap;
- the delivery of disability and diversity awareness training to all public facing staff;
- improving the census to ensure data on disability is consistent and available;
- campaigning for inclusive Public Transport;
- the introduction of an Occupational Therapy approach to welfare assessments;
- capital investment in Special Education Schools;
- ensuring Impact Assessments assess how policy assists each section 75 group rather than protect against harm;

- ending cruel and benefit punitive sanctions and replacing them with an incentive-based system;
- removing the two-child limit and the benefits cap;
- ending outsourced medical assessments for welfare;
- ending frequent, repetitive assessments for people with lifelong, permanent, or deteriorating conditions;
- advocating for an increase in the Carer's Allowance, bringing it into line with Job Seekers' Allowance;
- supporting funding and legislation to entitle carers to respite provision so that they can have regular breaks from the responsibility of providing care;
- pushing for a Northern Ireland approach to identify and support child carers and a strategy to ensure there is alternative care provision where suitable;
- ensuring that the role played by carers is fully recognised.

The DUP committed to:

- removing barriers to the full participation of d/Deaf and disabled people in life;
- closing the disability employment gap;

- ensuring the early identification of special educational needs, appropriate support, and enhanced training for teachers and assistants;
- implementing a new model for learning disability services, which will be able to adapt to and embrace the findings of investigations and a public inquiry into the failings at Muckamore Abbey Hospital;
- developing a world-leading psychological trauma service;
- delivering increased Intermediate Care at Home;
- developing and promoting social care as an attractive career with training, professional development, and progression;
- delivering appropriate support and advice for unpaid carers to help meet their financial, psychological, and social needs.

The SDLP committed to:

- parity of esteem for mental health services and that these services need to be properly resourced;
- accessible housing and transport;
- extend and enhance welfare mitigations;
- the removal of barriers to the full participation of d/Deaf and disabled people in life;
- involving d/Deaf and disable people in planning for the response to Covid-19.

Sinn Féin committed to:

- incorporating the UNCRPD into law;
- advancing a human rights framework with respect to policy and legislation;
- protecting of d/Deaf and disabled people from direct and indirect discrimination;
- advancing accessibility in transport, housing, and health;
- closing the disability employment gap;
- investing in independent living;
- the deinstitutionalisation of d/Deaf and disabled people combined with appropriate community support;
- accessible provision for victims of domestic violence;
- adequate support for carers;
- reducing waiting times for assessments and the adequate resourcing of support for students with special educational needs;
- investing in additional educational psychologists.

People Before Profit committed to:

- the incorporation of the UNCRPD into domestic law;
- advancing legislation to protect d/Deaf and disabled people from direct and indirect discrimination;
- adequately funded respite provision;

- an end to the institutionalisation of d/Deaf and disabled people and enhanced community support packages;
- the involvement of d/Deaf and disabled people in Covid-19 planning;
- increasing funding for mental health services;
- implementing a rights-based approach to disability;
- the provision of decent social care.

The Ulster Unionist Party committed to:

- removing barriers to the full participation of d/Deaf and disabled people in life;
- closing the disability employment gap;
- transforming of mental health services;
- addressing the healthcare emergency.

Findings from Stakeholder Engagement

Three direct engagement sessions were held with 143 d/Deaf and disabled people, their representative organisations, and key stakeholders[170].

The sessions were as follows:

- the Rights of d/Deaf and Disabled People session was attended by 56 people on 24 November 2021;
- the Rights of d/Deaf and Disabled Women session, which was delivered in partnership with the WRDA, was attended by 69 people on 9 December 2021;
- d/Deaf and Disabled People's engagement with the Independent Panel on Welfare Mitigations was attended by 18 people on 15 December 2021.

The aims of the events were twofold. First, to assist the research team develop a wider understanding of the specific human rights issues faced by disabled people in Northern Ireland at present and how these may have changed since 2017. Secondly, to assist the research team to identify priorities, gaps, and developments in the research and to inform the analysis and recommendations emerging from the project.

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[170] Stakeholder engagement sessions were held online due to Covid-19.

Participants were identified via a snowball sampling strategy using email, Facebook, Twitter and LinkedIn. Each event focused upon identifying the top three priorities of participants:

- policy developments since 2017;
- shortfalls in legislation, policy, and programme development;
- the lived experience of d/Deaf and disabled people.

Key themes from the stakeholder events included:

1. Incorporation of the UNCRPD into Law

Participants noted that historically there has been an absence of a strategic, co-ordinated human rights-based approach towards the implementation of the Convention within NI. There is currently no agreed framework for the implementation of an adequately resourced disability strategy [171]. Although activity to develop a Disability Strategy is underway, it has yet to be published.

The continued lack of progress regarding the incorporation of the UNCRPD into domestic law was linked to delays in both the development and implementation of subsequent disability strategies and the absence of progressive change to improve the lives of d/Deaf and disabled people. Access to funding was cited as a significant challenge.

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[171] Flynn, E. and Artstein-Kerslake, A. (2017): State Intervention in the lives of people with disabilities: the case for a disability-neutral framework, *International Journal of Law in Context*, 13: 39-57.

2. Participation in Decision Making

Participants raised the importance of participation by d/Deaf and disabled people in decision making. The importance of participation is core to the UNCRPD and represents a key theme within the UN Committee's concluding remarks in 2017.[172] Participation and engagement were a key priority for d/Deaf and disabled people and DPOs[173].

It is therefore essential the NI Executive and Assembly improve the participation and engagement of d/Deaf and disabled people and their representatives at all levels in order to progress a right based approach to disability policy and legislation. d/Deaf and disabled people need to have power and control over all areas of our lives. Participants expressed a view that the absence of d/Deaf and disabled people in decision making is a significant barrier to change.

Stigma, discrimination, limited financial opportunities, limited support and limited accessibility of physical infrastructure were cited as barriers to participating in decision making. The lack of opportunities for d/Deaf and disabled people to participate in decision making has been associated with the lack of progress in the realisation of rights.

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[172] 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, CRPD/C/GBR/CO/1, paragraphs 9-10.

[173] Flynn, E. (2011): From Rhetoric to Action Cambridge University Press.

Participants referred to institutionalised ableism and the need to involve d/Deaf and disabled people in decision making to resolve these challenges. Participants noted that policy design and development does not always address the needs and requirements of d/Deaf and disabled people. Examples include the lack of a clear policy on inclusive education, the absence of policy approaches to guarantee access to transport and physical environments, and the low priority given to access to healthcare.

3. Retrogression of Existing Rights

In the context of:

- the continued negative impact of Welfare Reform;
- reductions of social care funding;
- closure of the Independent Living Fund to new applicants;
- continued lack of accessible transport and public services;
- the impact of Brexit on the retrogression of rights;
- the Impact of the Covid-19 crisis including the collapse of services, inappropriate us of DNRs and withdrawal of medical treatment;
- the ongoing impact of the reduction of public finance budgets and austerity on public service delivery;
- under-resourcing of DPOs.

The NI Executive and Assembly have not provided a strategy to prevent retrogression of the rights of disabled people. It is not clear, yet, what the outcomes of the Disability Strategy will be and to what consideration will be given in the Strategy to the UNCRPD. However, the Disability Strategy Expert Advisory Panel have recommended that the Strategy explores ways in which the UNCRPD can best be given legal effect in Northern Ireland[174].

4. Dignity, Choice and Control

Dignity, choice and control are of extreme importance to d/Deaf and disabled people. Dignity, choice and control is relevant to the following Articles of the UNCRPD: 12 Equal recognition before the law[175],14 Liberty and security of person[176],15 Freedom from torture or cruel inhuman or degrading treatment[177], 19 Independent Living[178], 23

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[174] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.12 (accessed 10 October 2021).

[175] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 1 (accessed 4 November 2021).

[176] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 14 (accessed 4 November 2021).

[177] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 15 (accessed 4 November 2021).

[178] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 19 (accessed 4 November 2021).

Respect for home and family[179], 25 Health[180] , 26 Habilitation and rehabilitation[181], 28 Adequate Standard of Living.

Key issues include:

- implementation of the Mental Capacity Act (NI);
- the application of capacity legislation for children and young people;
- deprivation of liberty;
- inhuman and degrading treatment;
- use of restraint and seclusion;
- abuse in residential and community settings;
- resettlement from long-stay hospitals and assessment and treatment units;
- enjoyment of home and family life;
- health inequalities and mortality rates;
- lack of habilitation for children and young people;
- participants also raised the importance of choice and having control over their lives.

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[179] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 23 (accessed 4 November 2021).

[180] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 25 (accessed 4 November 2021).

[181] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 26 (accessed 4 November 2021).

5. Accessibility

Accessibility is essential to ensure that d/Deaf and disabled people can fully participate in society. Articles of the UNCRPD including: Article 4 General obligations[182], Article 9 Accessibility[183], Article 20 Personal Mobility[184], Article 24 Education[185], Article 27 Work and employment[186], Article 28 Adequate standard of living and social protection[187], Article 29 Participation in Public Life[188], Article 30 Participation in cultural life, recreation, leisure and sport[189], all raise issues in relation to accessibility.

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[182] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 4 (accessed 4 November 2021).

[183] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 9 (accessed 4 November 2021).

[184] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 20 (accessed 4 November 2021).

[185] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 24 (accessed 4 November 2021).

[186] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 27 (accessed 4 November 2021).

[187] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 28 (accessed 4 November 2021).

[188] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 29 (accessed 4 November 2021).

[189] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 30 (accessed 4 November 2021).

The main areas of concern include:

- decision making;
- personal mobility;
- transport;
- education;
- information;
- digital services;
- rural areas;
- access to and privacy in health and social care communication;
- housing;
- public office and electoral processes;
- restricted access to public services and social support.

Transportation was raised consistently as one of the major barriers limiting d/Deaf and disabled people’s ability to live independently and be included in the community. The problems with transportation were not limited to any one type of transport and problems were raised with the unaccommodating hours of door-to-door transport, the lack of physical access for public transport, prohibitive costs of private transport (particularly taxis and minibuses), and the lack of understanding and awareness of disability by many people who work for transport companies.

Lack of access to transport was viewed as a barrier to social and economic inclusion. Participants raised both physical and attitudinal barriers to accessing transport. Participants noted that standards of accessibility were often narrowly defined and narrowly addressed. Wheelchair users noted that it is almost impossible to travel together due to limited access to wheelchair space. The use of public transport was described as stressful, and barriers to accessibility were referred to as demoralising.

Participants raised the continued lack of information in accessible formats, particularly relating to health.

Participants referred to the negative impacts of unsuitable housing on their lives. Living in inappropriate housing has negative impacts on quality of life, and physical and mental health.

Participants noted that there were challenges in accessing social housing due to the lack of appropriate stock and the challenges in navigating the points system.

6. Independent Living

Participants raised concerns regarding the availability of resources and support to facilitate independent living. An emphasis was placed upon the absence of community provision. Participants raised issues with respect to the lack of choice of where to live and whom to live with. The ongoing delays of the resettlement from long stay hospitals continue to be of concern.

The closing of the Independent Living Fund to new applicants was of concern, as were inconsistencies with respect to direct payments.

Participants raised concerns regarding barriers to home owning by d/Deaf and disabled people and the reliance on precarious private housing.

7. The impact of Covid-19

Participants reported that the coronavirus pandemic has amplified inequality and led to declining mental and physical health. Access to health and social care collapsed. Participants reported significant challenges in accessing food and healthcare. Participants noted the tension in the approach of protecting the vulnerable during the Covid-19 crisis whilst at the same time removing services for vulnerable people which had a detrimental impact upon their physical and mental health.

Not all people who felt they should be shielding received shielding letters which meant that some people were further isolated from provision.

Participants:

- referred to the erosion of their human rights during the pandemic;
- reported that in instances when social care was available or resumed, they felt powerless and dependent on others to maintain standards to prevent the spread of Covid-19. This caused significant anxiety;
- reported that isolation had a negative impact on their lives and that they had no option but to try and sleep away hours of the day.

People with autism whose day centres closed have reported declines in mental health and high levels of distress with knock on impacts on carers.

Participants:

- reported that their lives were valued less than others, using language such as left behind and forgotten;
- referred to the inappropriate use of DNR’s;
- reported challenges in accessing public transport, maternity services, GP surgeries, emergency telephone helplines and vital pandemic-related public information;

- reported that annual health check-ups were cancelled and that the provision and repair of aids was disrupted and cancelled.

Visually impaired people reported challenges in accessing information regarding the pandemic, vaccination programmes and social distancing. Participants reported:

- challenges in accessing public transport and a reliance towards private taxis which are scarce for wheelchair users;
- feeling "at the end of the list" when it came to consideration of provision for health and social care, access to services and vaccines.

The impact of masks on those who are d/Deaf or hard of hearing was also raised by participants.

Participants reported that they were afraid to leave the house due to fears of becoming infected with Covid-19 and dying.

8. Education

Access to education and appropriate support was raised by participants. Participants raised challenges with respect to ongoing segregation, bullying, hate crime and hate speech.

9. Health

Health was one of the key topics raised in the stakeholder discussions with a range of concerns identified. Many concerns reflected the priorities of the UN Committee. Participants expressed views demonstrating that:

- the health service tends to provide a negative perception of disability (medical model) which others then adhere to;
- the collapse of health and social care during the ongoing Covid-19 crisis caused significant disruption and resulted in a decline in physical and mental health;
- d/Deaf and disabled people experienced significant challenges in accessing food and medicine and faced isolation during the Covid-19 pandemic;
- DNRs were used inappropriately;
- access to medical treatment was restricted during Covid-19;
- there was a lack of transparency in decision making;
- the lack of accessible health information;
- underfunding and difficulties in accessing mental health provision;
- examples when health providers communicated with carers rather than the d/Deaf and disabled person;

- the inefficient provision of information including appointment letters in inaccessible formats. Positive examples which were highlighted included the provision of appointment reminders by phone and email instead of letter.

10. Social Security

Participants stressed that d/Deaf and disabled people are living in poverty and are experiencing a lack of employment opportunities. It was highlighted that instead of these problems being recognised, that d/Deaf and disabled people are stigmatised as ‘benefit scroungers’ and ‘risky’ in terms of employment.

Participants linked economic wellbeing to overall wellbeing and noted that access to finance could be a barrier to participation. Lack of income was linked to feelings of depression and mental health challenges. Welfare reform has left participants worse off, and many consider that the current system is complex and dysfunctional. Application forms are challenging, and the PIP assessment process is degrading and harmful to mental health. One keynote speaker described being assessed for PIP while in bed recovering from an operation and facing persistent attempts for them to get out of bed and walk.

PIP assessments have been associated with a decline in mental health and severe anxiety, feeling sick in advance of assessments and experiences of insomnia. Participants referred to the insidious brutality of accessing PIP, referring to the process as degrading. Appeals were highlighted as particularly stressful.

Some participants described experiencing a mental health crisis as a result of engaging with the social security system. The irregularity of Universal Credit (UC) payments was cited as problematic[190].

Participants highlighted having to choose between food and heating and relying on food banks. d/Deaf and disabled people reported falling behind with their household bills, experiencing poor housing, and increasing costs. Participants referred to the work capability assessment as stressful, leading to anxiety and mental health challenges referred to as socially induced stress. Participants referred to the process of applying for benefits as exhausting.

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[190] Under the legacy benefits system for example those claiming Income Support (IS), or Job Seekers Allowance (JSA) benefits were paid on a fixed fortnightly basis. The claimant knew they would receive their benefit on the same day every two weeks. 26 payments over a 52 week period (every two weeks) as opposed to just 24 payments over a calendar year associated with the Universal Credit Calendar month payments schedule. Universal Credit claimants and can wait up to 17 days for another payment since they last received payment of the benefit. This means claimants have to wait longer to receive the money putting much greater pressure on household budgets. Claimants lose a month’s benefit per year as compared with the payments of older benefits such as JSA and IS.

11. Discrimination

Participants raised significant and distressing examples of discrimination. This included discrimination in employment and in access to services. Participants highlighted significant challenges in accessing legal redress and were vocal about the impact of stigma, discrimination, isolation, marginalisation, abuse, violence, neglect on their lives. Participants referred to challenges in being perceived as different, and the belief among many that to be different is to be inferior. Experiences of discrimination were cited as stimulating downward spirals of physical and mental health.

Participants reported that there was an absence of access to information and support through which to challenge discrimination.

Participants noted the importance of awareness raising in challenging stereotypes which would reduce discrimination.

12. The Rights of d/Deaf and Disabled Women

Participants referred to the systemic discrimination against d/Deaf and disabled women. Participants were vocal about the devastating impact of austerity on the delivery of public services, the severe impact of welfare reform and the challenges in accessing PIP.

Women raised specific issues with respect to abuse and domestic violence and the absence of appropriate provision. Participants described increases in domestic violence and abuse during the Covid-19 crisis. Isolation led to horrific experiences for many d/Deaf and disabled women. Participants reported that isolation and restricted access to pre-existing support networks, increased dependency on abusers, including abusive carers.

Women were vocal on the impact of hidden disabilities and being referred to as “too disabled to work” but “not disabled enough”. One speaker referred to being asked to “look more disabled” for a press interview.

Participants described how the cost of living for d/Deaf and disabled women is increasing, as income is decreasing. Many d/Deaf and disabled women were not eligible to access the government’s £20 increase to Universal Credit. Discriminatory work practices and the Executive’s failure to implement fair employment regulations led to unemployment, reduced work hours, and reduced pay.

d/Deaf and Disabled women reported becoming more reliant on partners, family members and friends for financial support and care needs. Despite this, d/Deaf and disabled mothers were predominantly responsible for domestic duties and childcare and described experiencing declining physical and mental health.

Participants reported challenges in sourcing food, basic household products, medication, and menstrual hygiene products. Participants raised issues regarding the accessibility of women’s health services including sexual and reproductive healthcare services. Facilities and the approach to examination were referred to as inaccessible.

13. The rights of d/Deaf and disabled children

The absence of access to play and toileting facilities was a significant concern for participants. Participants highlighted challenges experienced by d/Deaf and disabled children in accessing leisure and recreational activities. Participants highlighted that d/Deaf and disabled children participated in fewer activities and had less opportunities to participate fully in school and in the community.

14. Employment

Participants raised concerns regarding:

- the disclosure of disability including stigma and the fear of discrimination, particularly for those with mental health conditions;
- significant and distressing examples of discrimination in employment which have had significant negative impacts upon mental health. There were particularly distressing examples with respect to mental health;

- challenges associated with accessing employment including stereotypes associated with disability acting as a barrier to employment and progression;
- stigma as a barrier to accessing employment, which could induce feelings of shame and worthlessness;
- challenges in the physical working environment including co-working spaces alongside perceived expectations with respect to hours as barriers within the employment environment;
- inability to secure the reasonable adjustments which they require highlighting barriers in accessing appropriate equipment.

Transport and physical barriers within the buildings were referred to as barriers to employment.

15. Other Cross-cutting issues

There were several cross-cutting themes that came through in the engagement that d/Deaf and disabled people felt strongly about. These themes are listed below.

Article 8[191] Awareness raising

Participants referred to:

- the lack of awareness of positive and realistic representations of d/Deaf and disabled people;
- the absence of targeted long-term awareness raising campaigns and strategies;
- the lack of involvement of d/Deaf and disabled people in the development of awareness raising campaigns;
- the persistence of negative attitudes and stereotypes.

Article 31[192] Statistics and Data Collection

Participants referred to the lack of consistent and comparable data on disability prevents benchmarking and measuring progress based on relevant and jointly agreed indicators. This is not only a barrier to policy and legislative development but is also a barrier to accessing funding.

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[191] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 8 (accessed 4 November 2021).

[192] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 31 (accessed 4 November 2021).

Article 21[193] Freedom of expression, opinion, and access to information

Participants outlined barriers in accessing information is a long-standing issue for d/Deaf and disabled people.

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[193] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 21 (accessed 4 November 2021).

Articles 1-4 Purpose, Definitions, Principles and Obligations

> *"The UK and NI governments fail to uphold the UNCRPD, we are constant targets when it comes to cutting public money and services. There are no education programmes for teaching disabled people their rights. The attacks on the Human Rights Act will detrimentally affect us. Our access to healthcare is woeful. The strain on the NHS actively harms us".*
>
> **Disabled woman, aged 25-29**

Article 1[194] outlines the purpose of the present Convention to promote, protect and ensure the equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Whilst the UNCRPD does not provide for any direct sanctions to be taken against a government for non-compliance, it does provide a set of minimum standards which the government has agreed to implement. These can be used to support legal arguments and as an aid to interpret the law on human rights within the court system.

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[194] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 1 (accessed 4 November 2021).

The UN Committee raised the following concerns[195] with respect to Articles 1-4[196]:

- the insufficient incorporation and uneven implementation of the Convention across all policy areas;
- the lack of consistency across the State party in the understanding of, adaption to and application of the human rights model of disability and its evolving concept of disability;
- the absence of a comprehensive and cross-cutting review of the State party's legislation and policies, including within the devolved governments, in order to harmonise legal content and practice with the Convention;
- the existing laws, regulations and practices that discriminate against persons with disabilities;
- the lack of information on policies, programmes and measures that will be put in place by the State party to protect persons with disabilities from being negatively affected when Article 50 of the Treaty on European Union is triggered.

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[195] 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, CRPD/C/GBR/CO/1, paragraphs 6-11, p.3 (accessed 5 November 2021).

[196] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 (accessed 4 November 2021).

The Committee recommended the incorporation of the UNCRPD into law combined with an appropriate response to the obligations enshrined in the Convention. The Committee recommended that new and existing legislation incorporates the human rights model of disability policy across all levels, a cross cutting review of policy and legislation in line with Article 1, and measures to ensure that people with disabilities are protected against discrimination alongside measures to address the challenges of Brexit[197].

With respect to NI, the Committee noted the lack of Executive-led initiatives to address the inclusion and living conditions of people with disabilities and recommended the implementation of a strategic approach to improve the living conditions of people with disabilities[198]. The Committee raised concerns regarding the challenges facing organisations working with those who have disabilities with respect to access to support and decision making noting the absence of mechanisms through which to ensure the effective participation of d/Deaf and disabled people.

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[197] 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, CRPD/C/GBR/CO/1, paragraphs 7-11, p2-3 (accessed 5 November 2021).

[198] Ibid, paragraph 8.

The Committee recommended that these matters should be addressed through the allocation of resources to support organisations representing people with disabilities, mechanisms through which to promote participation in decision making, and the development and implementation of objective, measurable and financially resourced strategic plans.

The UN Committee has drawn attention to the lack of legislative progress with respect to the reform of equality law, particularly in NI. Progress has been made in the context of moving towards a new Disability Strategy which has been guided by an expert advisory panel appointed by the Minister for Communities and a co-design group[199].

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[199] The Department for Communities (DfC) established a Disability Strategy Co Design Group in order to advise the Department on the development and drafting of a new Disability Strategy. The Group was established in order to:

- help DfC to understand the experience of, and issues faced by, people with disabilities for whom the Strategy will deliver;
- ensure the lived experiences of people are appropriately reflected in the Strategy, obtain the views of relevant stakeholder groups on its content and themes, consider urban/rural implications, provide feedback on these to DfC and ensure these views are appropriately reflected in the Strategy prior to DfC issuing it for public consultation;
- work alongside DfC to ensure that the draft Strategy addresses the themes, content, key actions and gaps in provision that have been identified by the Expert Advisory Panel and wider stakeholder engagement;
- throughout development of the Strategy, maintain focus on addressing the themes and biggest issues affecting disabled people in NI;
- support DfC in the production of an evidence-based Strategy and action plan which is outcomes-based, appropriately aligned to Programme for Government and takes account of international obligations including UNCRPD and, in particular, UNCRPD General Comment No.7;

In March 2020 the Independent Mechanism for Northern Ireland (IMNI) announced their commitment to establishing a Disability Forum[200]. The purpose of the Forum is to assist the IMNI in their work to fulfil the independent monitoring role within Article 33 and to inform and co-ordinate engagement with the State Party towards supporting and challenging government to give effect to the UNCRPD in NI. The establishment of the Forum sought to realise the intent of the UNCRPD Committee's general comment no. 7[201] and the importance of prioritising the views of d/Deaf and disabled people. The first meeting of the group was held on the 4 March 2021[202].

There remains a significant gap in the inclusion of d/Deaf and disabled people in decision making within the NI context. This has been exemplified by reported challenges in the co-design process.

- constructively challenge DfC throughout the development of the Strategy and action plan, and prompt all NICS departments contributing Strategy actions to target resources at the priority areas which need to be addressed; and
- assist DfC in developing detailed proposals for the establishment of robust monitoring and reporting mechanisms with meaningful involvement from representatives of the sections of society at which the Strategy is targeted.

DfC (ND): Disability Strategy co-design group - terms of reference (accessed 30 November 2021).

[200] ECNI (2020): IMNI Disability Forum (accessed 15 October 2021).

[201] CRPD Committee (November 2017): 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, paragraph 13 (accessed 22 October 2021).

[202] ECNI (2020): IMNI Disability Forum (accessed 15 October 2021).

Fundamental changes are required in order to address procedures and processes that continue to reflect the unequal balance of power which limits the access of d/Deaf and disabled people to decision making. New and inclusive dialogue is required if the UNCRPD is to be advanced.

The authors of this report propose that the NI Executive should:

- outline a clear strategy and time scale for the incorporation of the UNCRPD into law;
- progress the Disability Strategy with appropriate levels of resources;
- implement a human rights model of disability;
- ensure d/Deaf and disabled people are fully engaged in decision-making processes.

Article 4 General Obligations

> "*Disability is severely underfunded and needs reform. Statutory bodies need to invest and support the most vulnerable in our society, that includes more wide training for people who have authority. We live in a society where people think it's ok to abuse disabled people and get away with it. More investment, support and training are key to moving forward".*
>
> **Disabled woman carer with long-term health condition, aged 40-44.**

Article 4[203] of the UNCRPD requires States Parties to adopt all appropriate legislative, administrative and other measures for the implementation of the rights in the Convention. The UNCRPD Committee expressed concerns in 2017 regarding the insufficient and uneven implementation of the Convention across the UK including by the devolved administrations[204].

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[203] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 4 (accessed 4 November 2021).

[204] 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, CRPD/C/GBR/CO/1 (accessed 5 November 2021).

States have an obligation to closely consult and actively involve d/Deaf and disabled people in the development and monitoring of policy and legislation.[205]

The Programme for Government (PFG) Draft Outcomes Framework consultation 2021 recognised Disability as a Key Priority Area[206] with the emphasis placed upon improving the quality of life for those of us with disabilities, empowering people to have more influence over their own lives and providing opportunities to participate in decisions that affect them.

Aligned to concerns of disabled stakeholders, ECNI expressed concern that disability equality did not appear as a key priority under the outcome 'We have an equal and inclusive society where everyone is valued and treated with respect'[207]. Instead, disability equality was situated under the outcome 'We have a caring society that supports people throughout their lives'[208].

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[205] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 4.3 (accessed 4 November 2021).

[206] NI Executive (2021): Consultation on the Programme for Government draft Outcomes Framework p.27 (accessed 20 October 2021).

[207] Ibid, p.16.

[208] Ibid, p.27.

This latter formulation and approach are interpreted as representing a medical model approach rather than a social and/or human rights model based on the rights outlined in the UNCRPD. The proposed disability strategy is the main delivery mechanism[209].

Article 4 (2) pertains that State parties must take measures to the maximum regarding the resourcing of the progressive realisation of rights[210].

DPOs are persistently underfunded and under-resourced[211]. The financial position of DPOs declined further in the context of the Covid-19 crisis[212]. This has led to increased pressures on sustainability and further pushes matters associated with disability towards the margins[213]. The UNCRPD Committee recommends that organisations representing d/Deaf and disabled people, including d/Deaf and disabled women and children are adequately resourced [214].

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[209] ECNI (March 2021): Response to the Executive's consultation on a Programme for Government Draft Outcomes Framework, paragraph 4.21, page 8.

[210] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 4.2 (accessed 4 November 2021).

[211] Disability Action (2021): DPOs are chronically underfunded (accessed 30 November 2021).

[212] Ibid.

[213] Disability Action (2021): DPOs are chronically underfunded (accessed 21 October 2021).

[214] 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, paragraph 11, p.3 (accessed 5 November 2021).

The Committee has called for the full involvement of DPOs in the planning and implementation of all measures which impact upon the lives of d/Deaf and disabled people[215].

Article 4(3) of the Convention states that “in the development and implementation of legislation and policies to implement the present Convention and in other decision-making processes concerning issues relating to people with disabilities State parties (Governments) shall closely consult and actively involve persons with disabilities”. Article 33(3) relates to the monitoring of national implementation and full participation of d/Deaf and disabled people in the independent monitoring framework[216].

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[215] 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, CRPD/C/GBR/CO/1, paragraph 11.a, p.3 (accessed 5 November 2021).

[216] In the case of Northern Ireland this refers specifically to the Independent Mechanism for Northern Ireland.

In 2017, the UNCRPD Committee published general comment no. 7 to clarify the importance of engaging directly with disabled people on matters which affect them[217]. The Committee noted that DPO's should be distinguished from organisations 'for' persons with disabilities[218] which provide services or advocate on behalf of them which in practice may result in a conflict of interest. General Comment no. 7 recognises the need to involve DPOs in decision-making processes.[219]

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[217] The UNCRPD Committee (comprising of 18 d/Deaf and disabled people who are acknowledged as human rights experts) will issue general comments to clarify how articles within the Convention should be understood and applied by governments who have signed up to the Convention. General comments are issued because there is evidence that governments do not understand how to interpret and apply the specific intent of some articles. Previous general comments have included: General Comment No. 1 clarifying how Article 12 'Equal Recognition before the Law' should be interpreted and understood; General Comment No. 2. on Article 9 'Accessibility'; General Comment No. 3 on Article 6 'Women and Girls with Disabilities'; General Comment No. 4 on 'Education'; General Comment No. 5 on 'Independent Living'; General Comment No. 6 on Article 5 'Equality and Non-discrimination'. General Comments are available at: https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx

[218] UNCRPD Committee (November 2017): 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', paragraph 13 (accessed 22 October 2021). The development of General Comment no. 7 originated in concerns raised by DPOs in NI that d/Deaf and disabled people were not being prioritised within decision-making processes. The DPOs in Northern Ireland advised the Committee on the following matters:

- the need to prioritise the participation of disabled people and their representative other organisations (DPOs) in any decision-making frameworks relating to the monitoring and implementation of the UNCRPD[218];
- the need to recognise the limited capacity of DPO's to respond effectively within existing decision-making frameworks and consultation processes on matter direct and indirectly impacting upon d/Deaf and disabled people;
- the importance of States parties (governments) resourcing and funding DPOs.

[219] UNCRPD Committee (November 2017): General comment No. 7, paragraph 15 (accessed 14 October 2021).

DFC has taken some positive steps with respect to the development of the new Disability Strategy. The Department established a Disability Expert Advisory Panel in September 2020 to make recommendations for further development. The members of the Panel included three d/Deaf and disabled people and academic experts on the UNCRPD[220]. A Co-design Disability Strategy Working Group was established to develop and expand further the recommendations and issues highlighted in the Panel Report.[221] The Group was expected to work closely with the Department for 15 months to develop the Disability Strategy due for full public consultation at the end of 2021.[222]

The establishment of a Northern Ireland Disability Forum to work with the Executive and Assembly to ensure that d/Deaf and disabled people have a leadership role in the development of policies and legislation which impacts on d/Deaf and disabled people was a key recommendation of the Disability Strategy Expert Panel[223].

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[220] DfC (2021): Disability Strategy expert advisory panel - terms of reference (accessed 14 October 2021).

[221] DfC (2021): Disability Strategy Co-design Group – Terms of Reference (accessed 14 October 2021).

[222] The Terms of Reference for the Co-design Group refer to a 14-member panel. However, this was increased to 15 to allow for the inclusion of an additional DPO. The DPO organisations are Omnibus Partnership, Centre for Independent Living Northern Ireland, Inclusive Mobility Transport Advisory Committee, My Way Access, Northwest Forum of People with Disabilities.

[223] DfC (2021): Disability Strategy Expert Advisory Panel Report and Recommendations, page 18 (accessed 14 October 2021).

One positive development has been the establishment of the Regional Disabled People's Health and Social Care Forum by the Department of Health.[224]

The Disability Advisory Expert Panel recommended that the NI Executive and Assembly should ensure that every consultation and engagement on matters affecting d/Deaf and disabled people takes account of the UNCRPD's committee's recommendations summarised in paragraph 94 of the General Comment.[225]

Historically, there has been no commitment to the allocation of resources to DPOs[226]. The following issues have been raised by DPOs and the Disability Strategy Expert Panel:

- funding to disability organisations is driven by service-based criterion as opposed to promoting advocacy managed and controlled by disabled people;

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[224] Patient and Client Council: Your Voice in Health and Social Care (August 2021), Regional Disability Forum (accessed 20 November 2021).

[225] General Comment No. 7 clarifies how disabled people should be directly involved and engaged in decision making processes relating to the monitoring and implementation of the UNCRPD with regarding to Article 4:3 and Article 33.3 (accessed 20 November 2021).

[226] Disabled Persons' Organisations/organisations of disabled people as understood and defined in paragraphs 10 and 11 of General Comment No 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention.

- DPOs have been funded on an ad-hoc basis for engagement with government departments in respect of reasonable adjustments and expenses related to attending one-off meetings or specific project;
- members of DPOs involved in government departmental working groups and other ad-hoc style committees attend on a voluntary basis and receive no remuneration beyond that specified above;
- there is no strategy for long-term core funding from government to DPOs;
- it is unknown to what extent resources will be allocated to DPOs as part of the forthcoming Disability Strategy or what measures proposed by the Disability Strategy Co-Design Working Group will be adopted.

The new Disability Strategy will have the overall aim of tackling inequalities and obstacles that affect the everyday lives of d/Deaf and disabled people[227].

The Disability Expert Advisory Panel has made the following recommendations:

- explore ways in which the UNCRPD can best be given legal effect in NI;

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[227] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.4 (accessed 10 October 2021).

- 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;
- explore ways in which the UNCRPD can be given legal effect through a Northern Ireland Bill of Rights.

The authors of this report would extend these recommendations to include the following actions by the NI Executive and Assembly:

- prioritisation of the incorporation of the UNCRPD into domestic law;
- development of a resourcing framework to address the chronic underfunding of DPOs.

Article 5: Equality and Non-discrimination

> *"A lot of people in Northern Ireland do not adequately understand disabilities, especially those which may be dubbed as 'invisible disabilities' this means that even if someone means well, they may often cause more problems than they solve"*
>
> **Disabled Man, aged 16-24.**

Article 5 of the UNCRPD requires that State Parties recognise that all persons are equal before and under the law and are entitled to the equal benefit and equal protection of the law without discrimination. Article 5 requires that State Parties prohibit discrimination on the basis of disability and guarantee d/Deaf and disabled people equal and effective protection without discrimination. States are required under Article 5 to take all appropriate steps regarding the provision of reasonable accommodation[228].

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[228] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 5 (accessed 4 November 2021).

The right to equality and non-discrimination is a human right and is essential to the practice of all other human rights identified within the UNCRPD for example Education (Article 24)[229] and Employment (Article 27)[230].

The UNCRPD Committee looked at how the UK was upholding the rights in law of d/Deaf and disabled people to promote equality and protect d/Deaf and disabled people from discrimination. The Committee raised concerns that the State Party's anti-discrimination legislation does not provide comprehensive and adequate protection against multiple and intersectional discrimination, including in access to housing. The Committee is concerned about the low level of redress in rulings in cases of disability discrimination. The Committee is concerned that the duty to make reasonable adjustments to the common parts of residential properties in the Equality Act 2010 is not yet in force, and that persons with disabilities living in Northern Ireland are not adequately protected against direct and indirect disability-based discrimination and against discrimination by association.

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[229] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 5 (accessed 4 November 2021).

[230] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 27(accessed 4 November 2021).

In response the Committee recommended that the State Party incorporate legislative protection for multiple and intersectional disabilities on the basis of gender, age, race, disability, migrant, refugee and/or other status, and provide appropriate compensation and redress for victims, and sanctions proportional with the severity of the violation[231].

The UNCRPD Committee is particularly concerned regarding the disparity of treatment of d/Deaf and disabled people across the UK. It was acknowledged that the situation for d/Deaf and disabled people in Northern Ireland was of particular concern[232]. The Committee has concerns regarding gaps in anti-discrimination laws for d/Deaf and disabled people in NI and with respect to intersectional experiences of disability. The UNCRPD Committee has recommended that the disability equality law in NI is strengthened to provide the same standard of protection against disability discrimination afforded to other d/Deaf and disabled people living in the rest of the UK.

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[231] 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, CRPD/C/GBR/CO/1, paras 12 and 13, p.3 (accessed 5 November 2021).

[232] 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, CRPD/C/GBR/CO/1, para 16, p.3 (accessed 5 November 2021).

The Committee[233] also recommended that the Northern Ireland Executive reform disability rights law to reflect the recommendations made by the Equality Commission for Northern Ireland, in its ‘Strengthening Protection for Disabled People’ report (2012) [234], to protect persons with disabilities in Northern Ireland from direct and indirect disability-based discrimination and discrimination through association.

The legislative framework for disability equality is distinct in Northern Ireland in comparison to other regions of the UK[235]. The Disability Discrimination Act 1995 (commonly referred to as, the DDA) is an Act of the Parliament of the UK which has now been superseded by the Equality Act 2010 in all nations of the UK, except NI, with the result that d/Deaf and disabled people in NI do not enjoy the same level of protection and legal redress as their counterparts in Great Britain[236].

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[233] 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, CRPD/C/GBR/CO/1, para 17.b (accessed 5 November 2021).

[234] ECNI (2012): Strengthening Protection for Disabled People Proposals for Reform, p3-8 (accessed 23 October 2021).

[235] Equality matters are devolved to the Northern Ireland Assembly.

[236] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations. p.62. (accessed 10 October 2021).

The Equality Act 2010 (EA 2010), in effect a Single Equality Act, has been recognised as providing clarity and coherence to anti-discrimination legislation within Great Britain providing protection from various forms of disability discrimination in areas such as employment, the provision of goods and services, education, and premises. This clarity and coherence is absent in NI.

A review undertaken by the Equality Commission NI in 2014 concluded that there were seven significant areas of divergence between GB and NI as the result of the lack of progress with respect to the protections within the Equality Act 2010 with NI[237]including:

- definition of disability;
- perceived and associative discrimination;
- indirect discrimination;
- discrimination arising out of disability;
- intersectional discrimination;
- access to remedies;
- increased powers for tribunals.

To date there have been no attempts by the NI Executive and Assembly to address the deficit in disability equality legislative provisions in NI.

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[237] Cited in Byrne B., Harper, C., Irvine R. S., Russell H. and Fitzpatrick B. (2014): UNCRPD: Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD, pp.56-57 (accessed 23 October 2021).

The continued existence of diverse and separate pieces of legislation for different equality grounds results in the legal system in Northern Ireland being more complex, less accessible and, in some cases, affording weaker protections than those within GB[238]. For example, a person with mental health issues in NI would not necessarily be considered a d/Deaf and disabled person entitled to the protection of the law, whereas in GB a mental health condition is considered a disability if it has a long-term effect on normal day to day activity[239].

The Equality Commission for NI's 'Strengthening Protection for Disabled People - Proposals for Reform' (March 2012)[240] have not been implemented. The purpose of these proposals was intended to ensure that disability equality legislation in NI kept pace with equality legislation in GB (Equality Act 2010) and to ensure that disabled people had at least the same level of protection against discrimination as disabled people in the rest of the UK[241].

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[238] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations. p.67 (accessed 10 October 2021).

[239] UK Government (ND): When a mental health condition becomes a disability.

[240] ECNI (2012): Strengthening Protection for Disabled People Proposals for Reform, pp. 2-8 (accessed 23 October 2021).

[241] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendation, p.70 (accessed 10 October 2021).

The Commission's report also recommended that the UK government consider strengthening disability equality legislation across the whole of the UK to better meet the requirements of Article 5. The Commission proposed amendments to address the gaps in disability equality legislation in Northern Ireland to meet the standards of protection afforded to d/Deaf and disabled people in the rest of the United Kingdom (Great Britain and Northern Ireland) are as follows:

- simplify and bring consistency to the disability equality legislation;
- amend the definition of disability by removing the list of capacities thereby making it easier for disabled people to fall within the protection of disability equality legislation;
- improve protection against direct and indirect discrimination taking account of developments in disability equality law in Great Britain;
- provide protection for carers of disabled people and those perceived as having a disability;
- proving protection against harassment in accessing goods, facilities, and services;
- extending the duty on further and higher education providers to provide auxiliary aids and services to schools;

- proving additional protection for disabled tenants that would require landlords to make reasonable adjustments in communal areas (for example a hall entrance to a block of flats).[242]

The Commission also proposed that the NI Executive should consider how NI disability equality legislation should be strengthened beyond the provisions of the Equality Act 2010 to better to meet the requirements of Article 5 of the Convention. For example, the Commission's proposals recognised that the Equality Act 2010 does not legislate for complaints of discrimination on based on multiple grounds/intersectionality and urged that such provision to tackle such discrimination be introduced in Northern Ireland.[243]

The Human Rights Indicators on the UNCRPD in relation to effective implementation of Article 5 specifically recommend that complaints alleging discrimination on the basis of disability should be considered on multiple grounds and that the information within this process should be desegregated.

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[242] ECNI (2014): Gaps in equality law between Great Britain and Northern Ireland pp.1-7 (accessed 2 December 2021).

[243] Office of the United Nations High Commissioner (OHCHR) (2020): Article 5: List of illustrative indicators on equality and non-discrimination, Structure 5.16 (accessed 23 October 2021).

Disaggregation should include the sex, age, disability, ethnic background, language, nationality, migrant status, refugee status, asylum-seeker status, socioeconomic status, geographical location or place of residence (urban/rural area), religion, marital and family status, sexual orientation and gender identity of complainants.[244]

Further, the UNCRPD human rights indicator for Article 5 emphasises that plans to promote equality for all d/Deaf and disabled people should, in particular, focus upon those groups which are most at risk of discrimination, highlighting examples such as women and girls, people with learning (intellectual disabilities), people with mental health issues (psycho-social disabilities), LGBTQ+, people with disabilities, persons with disabilities belonging to disadvantaged socio-economic groups, persons with different types of impairments, persons living in remote and rural areas and displaced persons.[245]

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[244] United Nations (2020): Article 5: Human Rights Indicators on the UNCRPD, List of illustrative indicators on equality and non-discrimination (accessed 25 October 2021).

[245] Ibid. See Structure 5.15 and Annex ii.

In the 2014 report on compliance with the UNCRPD[246], it was positively highlighted that no tribunal fees had been introduced to NI, but that it remained the case that remedies for breaches of anti-discrimination law are largely restricted to financial compensation. The recommendation in the report that remedies to change behaviour should be introduced remains a valid recommendation. Such remedies include the capacity for industrial tribunals to make recommendations for change which can be applied in the workplace[247].

The Equality Commission has a role in ensuring the effective application of Northern Ireland's equality laws including a duty to provide advice to anyone who believes they have experienced unlawful discrimination on various grounds, including disability. This means providing legal advice and, in some instances, representation to people taking cases of disability discrimination to Tribunals and Courts. The Equality Commission is constrained by limited resources from supporting every alleged case of discrimination.

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[246] Byrne B., Harper, C., Irvine R. S., Russell H. and Fitzpatrick B. (2014): Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD, paragrapha 6, p.57 (accessed 24 October 2021).

[247] The 2014 report, whilst raising issues with respect to discrimination, did not consider access to legal aid and support to challenge alleged disability discrimination.

In the period from 1 April 2020 to 31 March 2021, the Commission's Discrimination Advice Officers dealt with 2,962 enquiries, 49.5% of which were about disability discrimination[248]. The Commission must adhere to policy for the provision of Legal Advice and Assistance as provided for with respect to the relevant legislative framework.[249] Decisions on supporting cases are taken by Legal Funding Committees, made up of Commissioners. Committee members are rotated to ensure that each meeting has three committee members present. The Chair of this Committee rotates between all members[250].

The Commission may grant any application for assistance received from an individual who is an actual or prospective complainant or claimant in relation to proceedings arising from discrimination on grounds of sex, disability, race, religious belief, political opinion sexual orientation and/or age. The Commission can only grant assistance if the application comes within the statutory grounds specified in the relevant provisions of the enactments set out in the legislative framework. The Commission may grant an application for assistance to an individual, if it thinks fit to do so, on the grounds that:

(a) the case raises a question of principle;

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[248] ECNI (2021): Annual Report and Accounts. p.18 (accessed 24 October 2021).
[249] ECNI (2019): Policy for the Provision of Legal Advice And Assistance, paragraph 1 (accessed 2 December 2021).
[250] ECNI (ND): How We Support Cases (accessed 2 December 2020).

(b) it is unreasonable having regard to the complexity of the case or the Applicant's position in relation to the Respondent, or another person involved, or to any other matter to expect the Applicant to deal with the case unaided;

(c) or by reason of any other special consideration.

In January 2020, provision for early conciliation as a prerequisite for access to employment tribunals was enacted in Northern Ireland[251]. The change in law required that anyone who wishes to lodge a claim with the Industrial of Fair Employment Tribunal must first notify the Labour Relations Agency (LRA) and discuss the option of early conciliation. Both employees and employers can progress early conciliation. [252] Legal fees are not incurred when progressing through the Labour Relations Conciliation Service. The time limit for using the LRA Conciliation Service extends to six weeks. d/Deaf and disabled employees can have access to free legal representation and other support and do not therefore, incur financial penalties whilst seeking to resolve cases.

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[251] DfE (2020): Minister announces introduction of Early Conciliation in Northern Ireland for employment-related tribunals, 17 January 2020.

[252] Labour Relations Agency (2020): Early Conciliation (accessed 24 October 2021).

Disability Discrimination Case Study 1

In 2019 a case involving an employee with Asperger's Syndrome was able to benefit from free legal advice and support because the Tribunal ordered the employer and employee to use the Labour Relations Agency's (LRA) Conciliation Service. When the employee raised concerns with his employer, he was removed from his work team, despite having an exemplary work record. The Chair of the Industrial Tribunal stated that there were too many cases of disability discrimination relating to people with autism coming to Tribunals and ordered the employer (a public authority) to enter conciliation before re-entering the Tribunal[253].

It should be noted that the Conciliation Service provided by the LRA is voluntary. In this case the employee welcomed access to conciliation. The employer initially refused to engage with conciliation and only engaged once the complaint was lodged at Tribunal.

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[253] This case was jointly supported by Disability Action and the Northwest Forum of People with Disabilities. The grievance procedure associated with the case extended over two and half years. The client owned their own home and had no recourse to legal support. The client believed that as the Equality Commission had not taken his case that his circumstances did not amount to disability discrimination. However, he was advised by Disability Action and the Northwest Forum of People with disabilities that there was merit in advancing a case of disability discrimination. Both organisations sourced legal representation. Had the client not accessed the conciliation system he would have had no access to redress with respect to his circumstances. The Northwest Forum of People with disabilities would recommend that in cases of discrimination, legal aid should be expanded to include alleged discrimination cases where these are considered to have merit under the law.

The Tribunal process was more attractive to the employer in that the employer had access to resources such as legal representation which the employee did not[254].

The employee in this case had initially approached the Equality Commission who were unable to progress the case because it did not meet the criteria outlined earlier. This case demonstrates the importance of access to legal support for redress in cases of disability discrimination. There is also a need for clear communication regarding what exactly constitutes discrimination and sources of information, advice, and support. The case also demonstrates that it would be beneficial, in instances in which the Equality Commission is unable to respond to a case because it has not met the required criteria, that individuals are referred to DPOs such as Disability Action and the Northwest Forum of People with Disabilities which can intervene in such cases.

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[254] Northwest Forum of People with Disabilities Case Load, April 2019.

Disability Discrimination Case Study 2

The following case study is told in the words of a Disabled man with a long-term health condition aged 50-54 who participated in the qualitative research strand to inform this report and is told in the participant’s own words:

“I have been personally disadvantaged by the lack of parity of legal protection compared to other areas of the UK. In 2009 my employer required me to attend an occupational health assessment of my mental health. This direction came out of the blue, I was not ill, and I subsequently discovered that I was not told the real reason for it. This began an ordeal involving an increasingly toxic working environment which ultimately led to my transfer to a different Department in 2016. The reason given for the transfer was that over this period I had raised 4 separate but related grievances, none of which were upheld by my employer.

I received a written warning for major misconduct. In all 4 grievances, I asserted my right to be protected from disability discrimination. The Equality Commission NI subsequently supported my complaint of victimisation on grounds of disability. In response my employer attempted to have the case struck out on the basis that I was not in fact disabled and therefore did not qualify for protection under DDA.

They subjected me to the indignity of insisting sight of my full private medical records before conceding this point to the Tribunal.

The initial legal opinion was that I had a strong case, however a later review resolved that this was based on an assessment of English case law where claimants had benefited from protections under the Equality Act 2010 and crucially, the removal of a loophole relating to victimisation. The opinion was that the strength of my case was significantly weakened by this discovery, lack of parity in NI law.

The Equality Commission withdrew support for my case, and I eventually negotiated a settlement with the assistance of the Labour Relations Agency. The experience effectively ruined my career, it also led to a mental breakdown involving intense suicidal feelings that I was extremely lucky to survive. I think it is an absolute disgrace that the NI Assembly have done nothing to remove that loophole or address the many other ways that people with disabilities living in NI are disadvantaged by gaps in our book of law".

During 2020, only 8% of the cases where employees engaged voluntarily with the Labour Relations Agency (LRA) Early Conciliation service progressed to a Tribunal[255].

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[255] LRA (2020): Early Conciliation Comes to NI 27 January 2020 (accessed 24 October 2021).

The LRA found that fewer than half of employers in Northern Ireland trained managers to prevent or resolve workplace disputes. NI employers lag behind their counterparts in Great Britain in respect of dispute resolution, and where policies do exist, there is gap between policy and practice in the workplace[256].

Participants in the qualitative research informing this report told us about their experiences of tribunals referring to monetary and emotional costs:

> *"My one experience giving evidence in front of a Tribunal is that Judges clearly need training in disability human rights, including mental health. Also, I feel extremely lucky to have had the personal resilience and strength of feeling to assert my rights, repeatedly, throughout the long process and through the steps of the tribunal. Many disabled people will not be lucky enough to have the resources that enabled me to do this. Ultimately, I felt unable to represent myself alone against my employer's highly qualified legal team (paid for by the public). I think this is an indication of how heavily the deck is loaded against people with disabilities.*

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[256] LRA (2020): Improving Employment Relations, p.3 (accessed 24 October 2021).

By the time I found it necessary to assert my statutory rights, my mental health condition had (thank God) been properly diagnosed and was being effectively treated. I can't imagine what this experience would have done to me where that not the case. I certainly would not have had the fortitude to stand up for my basic human rights at an earlier stage in my illness, indeed the experience would have likely killed me".

Disabled man with a long-term health condition, aged 50-54.

In 2008, the European Court of Justice declared that a woman had been treated poorly by her employer because they refused to give her flexible working hours to enable her to look after her d/Deaf and disabled child[257]. She claimed that, although she did not have a disability, she was being discriminated against on the grounds of her relationship with her disabled child. The European Court ruled that it was unlawful for an employer to discriminate against someone because of their association/relationship with a d/Deaf and disabled person and that, in this case, the employer should have granted the employee flexible working hours to enable her to support her child.

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[257] S Coleman v Attridge Law [2008] C-303/06, European Court of Justice – Advocate General's Opinion.

This decision is now reflected in the provisions of the Equality Act 2010 in the Great Britain but has yet to be incorporated into Northern Ireland disability equality law. Furthermore, in Great Britain it is against the law for employers to ask questions about a person's disability that are not related to the specific job they are applying for[258]. In contrast, d/Deaf and disabled people in NI can be asked questions about their disability in an application form, a barrier which often discourages them from applying for jobs.

In Great Britain employers are not allowed to ask questions relating to a person's disability prior to the person taking up the post. However, Disability Action are aware of a case in which a person with a mental health condition had applied for 27 jobs and had disclosed their disability at the application stage. They were not successful in any of these applications. When the person applied for a similar job but did not disclose their disability they were successfully shortlisted for interview and appointed[259].

d/Deaf and disabled children who go to school in NI are not entitled to reasonable adjustments when accessing services provided by the school to meet their educational requirements (those children who do not have an assessed special educational need statement).

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[258] EHRC (No Date): Disability Discrimination, (accessed 26 October 2021).

[259] Disability Action Case Load 2019.

For example, a young person with multiple sclerosis requires a scribe to complete their exams as they have fatigue and visual impairment. In Northern Ireland the young person does not have the right to ask for such assistance[260] as there is no requirement under the law for the school to consider this type of reasonable adjustment. This is not the case in Great Britain.

In summary, the key legislative changes required include:

- the replacement of the concept of 'disability-related discrimination' with protection against 'indirect disability discrimination' and 'discrimination arising from disability';
- the amendment of the definition of disability to make it easier for deaf and disabled people to fall within the definition of disability to extend the protection of disability discrimination law to more d/Deaf and disabled people;
- the simplification of the disability equality legislation and the provision of consistency;
- the amendment of the definition of disability by removal of the list of capacities thereby making it easier for disabled people to fall within the protection of disability equality legislation;

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[260] Disability Action Case Load 2020.

- the improved protection against direct and indirect discrimination taking account of developments in disability equality law in Great Britain;
- the provision of protection for carers of disabled people and those perceived as having a disability;
- the provision of protection against harassment in accessing goods, facilities, and services;
- the extension of the duty on further and higher education providers to provide auxiliary aids and services to schools;
- the provision of additional protection for disabled tenants that would require landlords to make reasonable adjustments in communal areas (for example a hall entrance to a block of flats);
- increased protection for d/Deaf and disabled people against harassment or unfair treatment when accessing goods and services;
- protection for people, such as carers, friends, or family members, who are subjected to direct discrimination or harassment or unfair treatment due to their association with a d/Deaf and disabled person or for individuals because they are wrongly perceived to be persons with a disability;

- the prohibition of questions related to disability by employers, prior to making a job offer, to a d/Deaf and disabled person except in specified circumstances such as a specific requirement of the job;
- schools should be required to consider reasonable adjustments to make aids and services more accessible to d/Deaf and disabled students (those d/Deaf and disabled students who do not have an identified SEN).

Disability Discrimination Case Study 3

Because of the outcome of a case decided by the House of Lords in 2008 (the Malcolm Case)[261], the threshold for proving discrimination on the grounds of disability became much more difficult to prove. This case compared the treatment of a d/Deaf and disabled person with a non-disabled person in a similar situation to determine whether discrimination (less favourable treatment) had taken place. For example, if a restaurant had a policy of no dogs or pets allowed, the legal ruling above meant that a person with a guide dog or assistance dog would not be able to use the restaurant.

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[261] London Borough of Lewisham v Malcolm [2008] UKHL 43.

The judgement in the Malcolm Case[262] determined that no discrimination would have taken place since the person who would have accessed the restaurant with an assistance dog was treated the same as a non-disabled customer who may wish to have brought their pet into the restaurant.

The implication of the judgement, the requirement to compare the treatment of a disabled person to that of a non-disabled person in order to determine whether discrimination had taken place, now means that d/Deaf and disabled people in Northern Ireland have no protection against indirect discrimination.[263]

As a result of the outcome of the Malcolm Case[264] the law in Great Britain was changed following the introduction of the Equality Act 2010 which ensured that policies and practices, which unintentionally place d/Deaf and disabled people at a substantial disadvantage can be challenged. However, no comparable changes were made to the disability discrimination equality law in Northern Ireland.

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[262] EHRC (ND): The Malcolm Case (accessed 25 December 2021).

[263] Because the legal effect of the Malcom judgement, which impacts on interpretation of the Disability Discrimination Act 1995 (extant in Northern Ireland but not in Great Britain), has not been addressed.

[264] EHRC (ND): The Malcolm Case, (accessed 25 December 2021).

Disability Discrimination Case Study 4

A guide dog owner, was told by a taxi driver in Belfast that he did not allow dogs in his vehicle. The driver compared the volunteer with other non-disabled passengers who were dog owners and did not take into account that the guide dog enabled the person to live their daily life. Since the driver operated a general practice by not allowing any dogs in his vehicle, the effect of the Malcolm case meant that no disability discrimination had taken place. Under the disability equality law in Northern Ireland the volunteer is not able to pursue a case of disability related discrimination because comparing d/Deaf and disabled people with other non-disabled passengers has become the basis for proving that discrimination has taken place, despite the driver's practice putting the volunteer at a substantial disadvantage in using the taxi service[265].

Disability Discrimination Case Study 5

A Disability Action volunteer with cerebral palsy tried to enter his local pub in Derry/Londonderry, but the doorman refused to let him enter the bar, wrongly assuming that he had too much to drink. The volunteer explained to the doorman that he had cerebral palsy and that he was not drunk. However, the doorman refused entry.

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[265] Disability Action Case Load 2020.

As disability equality law in Northern Ireland stands at present, this refusal is not unlawful because the doorman was treating the volunteer as he would treat any non-disabled member of the public whom he suspected was drunk. However, the doorman's action did not take account of the volunteer's cerebral palsy, resulting in the less favourable treatment of the d/Deaf and disabled person.

The doorman's actions on this occasion were not intended to discriminate towards the d/Deaf and disabled person involved but rather reflected a general policy of not allowing anyone who was considered already drunk entry. Nonetheless because the volunteer was refused entry on the grounds that he was perceived as already being drunk, rather than being recognised as having cerebral palsy, meant that the disabled person was subjected to indirect discrimination and suffered less favourable treatment by not being allowed into the pub.

If the threshold for discrimination and indirect discrimination was the same as that in the Equality Act 2010, both individuals outlined in the above case studies could have pursued cases of disability discrimination[266].

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[266] Disability Action Case Load, 2020.

Recommendations proposed by the Disability Strategy Expert Advisory Panel include:

- urgent priority to be given by the Department for Communities to new disability equality legislation which fully incorporates the UNCRPD into domestic legislation;
- the acceptance and enactment of 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, including those proposals which better reflect CRPD rights than the Equality Act 2010, as recommended by the CRPD Committee;[267]
- introduction of 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[268].

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[267] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.70, (accessed 10 October 2021).

[268] Ibid, p.100.

Article 6 The Rights of d/Deaf and Disabled Women

> *"As a disabled woman I feel very underrepresented and marginalised and patronised by society".*
>
> **Disabled woman who is a carer aged 40-44.**

Article 6 recognises that women and girls are subject to multiple and cross-cutting discrimination and requires States to take action[269]. The UNCRPD Committee's General Comment No. 3 acknowledges specific human rights violations which impact disproportionately on women including denials of legal capacity and the absence of reproductive autonomy on an equal basis with other people[270].

The UNCRPD Committee recommends that the UK Government, in line with targets set out in the UN Sustainable Development Goals, adopt inclusive and targeted measures, including the collection and analysis of disaggregated data, to prevent multiple and intersectional discrimination of women and girls with disabilities, in particular those with intellectual

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

[270] UN Committee on the Rights of Persons with Disabilities (2015): General Comment No. 3 on women and girls with disabilities (CRPD/C/ GC/3), paragraphs 32, 44.

and/or psychosocial disabilities, in relation to education, employment, poverty, health, violence and access to justice[271].

The UN Committee concluded that the rights of women and girls had not been systematically mainstreamed into both the gender and equality agendas and highlighted the lack of measures and data with respect to the impact of multiple and intersectional discrimination of women and girls. The Committee recommended that the Executive mainstream the rights of d/Deaf and disabled women and girls with disabilities into both disability and gender equality policies in close consultation with organisations which represent women and girls with disabilities.

The UNCRPD Committee called on the NI Executive to establish measures to ensure equal access to justice and to safeguard persons with disabilities, particularly women, children, intersex people, and elderly persons with disabilities from abuse, ill-treatment, sexual violence and/or exploitation; and ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities[272].

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[271] 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, CRPD/C/GBR/CO/1, paragraph 19, p. 4.

[272] Ibid, paragraph 39(a), p. 8.

In response to these recommendations, the UK Government identified the Equality Act (2010) in force in England and Scotland, as providing means to identify those with protected characteristics including d/Deaf and disabled people[273]. The Equality Act (2010) is not in effect in Northern Ireland. The Disability Discrimination Act (1995) does not include any requirement to record disaggregated data. The UK and the NI Executive have yet to address the recommendation to consult with organisations of women and girls with disabilities and mainstream the rights of women and girls with disabilities into disability and gender-equality policies.

The Disability Strategy Expert Advisory Panel specified[274] the need to establish a Northern Ireland Disability Forum, including d/Deaf and disabled women and girls, to work with government in a leadership role. The Panel noted that there are barriers to d/Deaf and disabled women regarding access to health services including maternity services, cervical and breast screening services, and sexual and reproductive healthcare services[275].

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[273] Section 153 of the Equality Act 2010 provides for specific duties to be imposed on listed public authorities including (i) the collection of equality information (monitoring data); and (ii) the creation of equality objectives based on this information.

[274] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations. p.18 (accessed 10 October 2021).

[275] Ibid, p.117.

The Maternity Strategy[276] makes little reference to the experience of d/Deaf and disabled women. Health screenings such as cervical examinations and mammograms can be especially difficult with limited access to support, information, accessible equipment, or transport. Participants in the qualitative research to inform this report told us about the barriers which d/Deaf and disabled women experience in accessing healthcare:

> *"When it comes to people with protected status, the rights of disabled people generally come low down the lobby list of priorities, especially in a crisis. In particular areas such as health, this means that disabled women become doubly disadvantaged. The lack of regard shown to disabled women in the covid recovery plan is a clear example of this"*
>
> **Disabled man with a long-term health condition aged 50-54.**

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[276] DoH (2012): A strategy for maternity care in Northern Ireland 2012 – 2018 (accessed 29 October 2021).

The Disability Strategy Expert Advisory Panel have recommended the review and revision of current health policies and practices aimed at d/Deaf and disabled women and minority genders, placing emphasis on maternity services and health screening services, to ensure these are provided in an accessible manner for d/Deaf and disabled people[277]. Furthermore, the Panel also identified the need to support the active participation of disabled women and minority genders in the design, implementation and monitoring of the forthcoming Gender Equality Strategy Northern Ireland[278].

The Gender Equality Strategy is pending publication. However recommendations from the Gender Equality Strategy Expert Advisory Panel[279] highlight the importance of developing this strategy alongside other social inclusion strategies including disability[280]. It is important to note that, while there is a d/Deaf and disabled woman within the Expert Advisory Panel, there is no representative from a DPO within either the Expert Advisory Panel or the Co-Design Group[281].

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[277] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.118 (accessed 10 October 2021).

[278] Ibid, p.118.

[279] DfC (2021): Report from the Gender Equality Strategy Expert Advisory Panel (accessed 29 October 2021).

[280] Ibid, p.11.

[281] DFC (ND): Gender Equality Strategy (accessed 25 December 2021).

This is a weakness in approach from the perspective of advancing the rights of d/Deaf and disabled women. The Gender Equality Expert Advisory Panel Report has also indicated the importance of mainstreaming but highlighted significant challenges associated with the current approach to mainstreaming within the region which can be misinterpreted as being solely focused upon equal treatment[282].

The Northern Ireland Executive has a legal duty to introduce an anti-poverty strategy within Section 28E of the 1998 Act[283] as amended by the St. Andrews Agreement in 2006[284]. This duty could be employed to target resources on the basis of objective need. Such an action could play a significant role in addressing socio-economic disadvantage with respect to d/Deaf and disabled people and d/Deaf and Disabled women. The Executive has committed to developing an anti-poverty strategy. The Anti-Poverty Strategy Expert Advisory Panel[285] examined the potential for all social inclusion strategies to complement each other particularly with respect to educational opportunity and attainment, racial equality, disability, gender, rurality, and physical, emotional, and mental health.

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[282] Ibid, p.13-14.

[283] Northern Ireland Act 1998, Section 28E.

[284] Agreement at St Andrews, Annex B.

[285] DfC (2021): Report from the Anti-Poverty Strategy Expert Advisory Panel, p.14.

For d/Deaf and disabled women, the social inclusion strategies are of particular importance with reference to Article 6. In Northern Ireland, women of working age are more likely to be economically inactive, with sickness and disability being the second most common reason for this[286].

Of those in employment, d/Deaf and disabled women earn 22.1% less than able-bodied men, and 11.8% less than d/Deaf and disabled men[287].

Participants in the qualitative research to inform this report told us about the barriers d/Deaf and disabled women face and the impact upon their lives. Participants also referred to the lack of progress with respect to the inclusion strategies as problematic:

> "*One in two disabled women are in an abusive relationship yet it is never mentioned. Disabled women earn 22% less than non-disabled men and it is never mentioned. We don't have a gender equality strategy, a disability strategy, a violence against women and girls' strategy or childcare provision. These are all issues that make the lives of disabled women harder".*
>
> **Disabled woman carer with long-term health condition, 25-29.**

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[286] NISRA (2020): Women in Northern Ireland 2020 (accessed 30 October 2021).
[287] UK Women's Budget Group (20180: Disabled Women and Austerity (accessed 30 October 2021).

The Women's Policy Group NI is calling for the NI Executive Government to address the following issues:

- domestic violence and coercive control legislation that is fit for purpose;
- gender pay gaps and discrimination;
- ending the Universal Credit Two-Child Limit;
- the historic underinvestment in rural women;
- the under-representation of women in politics, public life, and decision-making;
- the rise of misogyny as a hate crime, particularly towards trans women, Black and Minority Ethnicities women and disabled women;
- standardising Relationship and Sex Education, and tackling rape culture;
- fully supporting and financing perinatal mental health services.[288]

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[288] Women's Policy Group (NI) (2020): Covid-19 Feminist Recovery Plan: Summary of Recommendations. 4.1, 1.2, 1.4, 3.2, 4.2, 2.3 (accessed 30 October 2021).

Evidence suggests that d/Deaf and disabled women are two times more likely to suffer physical abuse from an intimate partner than nondisabled women[289] and that d/Deaf and disabled women who experience domestic abuse face compound oppressions[290]. Women's Aid Northern Ireland report that 41% of women in refuges and 41% of women accessing outreach services have a disability[291].

The ongoing Covid-19 crisis has been connected to an increased risk of domestic violence against d/Deaf and disabled people[292]. A review by Public Health England in 2015[293] expressed a view that domestic violence against disabled women was likely under-reported. The report concluded that disabled people experience disproportionately higher rates of domestic abuse[294] than non disabled people'.[295]

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[289] Slayter, E. (2009): Intimate partner violence against women with disabilities: implications for disability service case management practice, Journal of Aggression, Maltreatment and Trauma 2009, 18: pp.182–199. doi:10.1080/ 10926770802675668 reference in Breckenridge et al. BMC Pregnancy and Childbirth 2014, 14:234. Available at http://www.biomedcentral.com/1471-2393/14/234.

[290] Nixon, J. (2009): Domestic violence and women with disabilities: locating the issue on the periphery of social movements, Disability and Society 2009, 24:77–89.

[291] Women's Aid Federation NI (2020): Annual Report 2019-2020.

[292] Hughes, K. et al (2012): Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. Hughes, K. et al. The Lancet, 2012, Vol. 379. 30; Trevillion, K. et al. (2012): Experiences of domestic violence and mental disorders: a systematic review and meta-analysis.

[293] Public Health England (2015): Disability and domestic abuse - Risk, impacts and response, p.7 (accessed 2 November 2021).

[294] Ibid, p.4.

[295] Ibid, p.4.

d/Deaf and disabled people may also experience domestic abuse in wider contexts and by greater numbers of significant others, including intimate partners, family members, personal care assistants and health care professionals. d/Deaf and disabled people also encounter differing dynamics of domestic abuse, which may include more severe coercion, control, or abuse from carers[296].

d/Deaf and disabled victims are more likely to report abuse from multiple perpetrators: one in five (19%) compared with one in twenty (6%) for non-disabled people.[297] There is a lack of specialist services for d/Deaf and disabled people experiencing domestic violence and many services are inaccessible[298]. For example, d/Deaf and disabled people who have communication challenges may experience barriers in accessing helpline support.

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[296] Ibid, p.4.

[297] SafeLives (2017): Disabled Survivors Too: Disabled people and domestic abuse. p.17 (accessed 2 November 2021).

[298] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.118 (accessed 10 October 2021).

There does not appear to have been a specific focus on domestic violence against d/Deaf and disabled people in Northern Ireland[299]. Research undertaken on behalf of the Equality Commission NI (2014) on UNCRPD compliance in NI reported that the absence of comment from stakeholders on Article 16[300] (UNCRPD Freedom from exploitation, violence, and abuse) issues is itself perhaps ‘a sign of a lack of government emphasis on what are difficult issues which many voluntary sector organisations are reluctant to engage’[301]. The report also indicated that, policies and programmes to deliver on Article 16 will need to have a clear basis in the particular experiences of violence, exploitation, and abuse of deaf and disabled people. Generic programmes and policies which include d/Deaf and disabled people, but which are not designed with them explicitly in mind are unlikely to satisfy the UNCRPD Committee as being compliant with Article 16.[302]

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[299] Byrne B., Harper, C., Irvine R. S., Russell H. and Fitzpatrick B. (2014): UNCRPD: Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD, p.100 (accessed 24 October 2021).

[300] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 16 (accessed 4 November 2021).

[301] Ibid, p. 100.

[302] Ibid, p.100.

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[303]. By contrast in the Republic of Ireland, d/Deaf and disabled people do not have to prove a specific diagnosis in order to have their gender recognised, and instead can self-identify[304]. d/Deaf and 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[305].

The Disability Strategy Expert Advisory Panel proposed the following recommendations:

- reform of 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;

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[303] NI Direct, (ND): Gender Recognition (accessed 25 December 2021).
[304] Gender Recognition Act (Ireland) 2015, s.10 (accessed 26 December 2021).
[305] Ellen Murray (2019): The Wrong Decisions: Trans Rights and Disability (accessed 26 December 2021).

- review and revision of 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 for the active involvement of disabled women and minority genders in the design, implementation and monitoring of the forthcoming Gender Equality Strategy Northern Ireland;
- development of Adult Safeguarding legislation in collaboration with d/Deaf and disabled people and their representative organisations, ensuring that all interventions are based on informed consent;
- increased accessibility for d/Deaf and disabled people in reporting an incident and throughout any resulting criminal process, including through provision of sign language interpreters, and independent support to fill out forms, etc;
- commissioning of further research to understand experiences of d/Deaf and disabled people in accessing domestic violence services and support and access legal redress;
- Increase funding and availability of independent advocacy to enable d/ Deaf and disabled people to report abuse in institutional settings.

The authors of this report would also recommend:

- investment in commissioning of fully accessible services for d/Deaf and disabled people experiencing domestic violence including access to redress.

Article 7: The Rights of d/Deaf and Disabled Children

> *"As a parent carer I already have to fight for every limited support we get for my child and social services for adults with disabilities is considerably less well funded than for children so I see no evidence that my son will have access to support required for independence in adulthood. Existence of places like Muckamore and huge lack of specialist accommodation in local towns means my son will have no option but to remain with us until we are no longer fit to care for him. Terrifying prospect and huge emotional burden on his sibling".*
>
> **Non-disabled carer aged 45-49.**

Overview

All rights within the UNCRPD apply to children. Article 7[306] specifically highlights that d/Deaf and disabled children should enjoy all human rights on an equal basis with other children. When decisions are being made, including decisions about education, the best interests of the child should be a primary consideration. The voice of the child should be heard, with disability and age-appropriate assistance provided if needed.

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[306] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 7 (accessed 4 November 2021).

The child's views on any decision affecting them should be given due weight on an equal basis to other children.

The UNCRPD Committee concluded that the NI Executive should take all necessary measures to ensure the full enjoyment of all human rights and fundamental freedoms by children with disabilities on an equal basis with other children. The Convention requires that the best interests of the child should be the primary consideration in all actions concerning children with disabilities and that the State Party should ensure that children with disabilities should have the right to express their views on all matters affecting them on an equal basis with other children[307].

In its concluding observations, the Committee expressed concern about the lack of a policy framework to address levels of poverty among families with children with disabilities, the failure to adopt a human rights model of disability in public policies and legislation with respect to children and young people with disabilities, the absence of indicators through which to monitor progress, the absence of a statutory duty to provide adequate childcare to children with disabilities and the reported increase in incidents of bullying, hate speech and hate crime against children with disabilities.

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[307] 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, CRPD/C/GBR/CO/1, paragraphs 20-12, pp 4-5.

The Committee recommended that the Executive should, in close consultation with organisations representing the views of d/Deaf and disabled children, develop and implement policies to eliminate higher levels of poverty experienced by families with children with disabilities, incorporate the human rights model of disability into all laws and regulations concerning children with disabilities, establish effective indicators and an independent monitoring mechanism, secure a statutory duty to provide sufficient and disability-sensitive childcare and strengthen measures to prevent bullying, hate speech and hate crime against children with disabilities[308].

The UN Convention on the Rights of the Child (CRC)[309] is an international human rights treaty adopted in 1989, ratified by the UK in 1991.

By following the CRC the UK, and as result NI, has agreed that public bodies should consider the best interests of the child when doing anything that affects children. CRC protects the rights of children in all areas of their life, including their rights to:

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[308] 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, paragraphs 20 and 21 (accessed 3 November 2021).

[309] UN Commission on Human Rights (1990): Convention on the Rights of the Child., 7 March 1990, E/CN.4/RES/1990/74 (accessed 1 February 2022).

- life, survival, and development;
- freedom from violence, abuse, and neglect;
- express their views in matters affecting them, including in legal proceedings;
- education;
- an adequate standard of living.

In NI, a piecemeal approach has been undertaken towards the implementation of the UN Convention on the Rights of the Child[310]. For example, child-related legislation may refer to the best interests of the child[311].

Poverty and Disadvantage

d/Deaf and disabled children and their families are more likely to live in poverty than their non-disabled counterparts[312]. It should be noted that a report by SCOPE, entitled 'Disability Price Tag Report 2019', estimated the additional costs for families with a d/Deaf and disabled child between £581 and £1000 per month[313].

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[310] UN Commission on Human Rights (1990): Convention on the Rights of the Child., 7 March 1990, E/CN.4/RES/1990/74 (accessed 1 February 2022).

[311] See Children's (NI) Order 1995.

[312] Child Poverty Alliance (2014): Beneath the Surface (accessed 4 November 2021).

[313] SCOPE (2019): The Disability Price Tag 2019, p.4 (accessed 4 November 2021).

The NIHRC's (2019) cumulative impact assessment of tax and social security reforms in Northern Ireland concluded that welfare reform has had a disproportionate impact upon households with at least one d/Deaf and disabled child, revealing that the average loss from welfare reform amounted to £2,000 per year compared to £50 per year in households with no disabled adults or children[314].

Participants in the qualitative research which informs this report, told us of their experiences of the higher costs of living experienced by d/Deaf and disabled people and the absence of measures to address this within the benefit system:

> "*The benefits system in NI does not take cognisance of the fact that disabled people spend at least 25% more on energy, power and heat than the able-bodied. When you cannot move, you become colder. You feel the pain more. You may not be able to afford enough home heating oil to have your heating sufficiently on a timer to keep you warm.*

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[314] NIHRC (2019): Cumulative impact assessment of tax and social security reforms in Northern Ireland (accessed 6 December 2021).

> *The NI Housing Executive applies unnecessarily stringent size limits on dwellings for those with disabilities - they do not take account of the additional space required for living aids and equipment; they fail to recognise that many married/living as if married couples with disabilities cannot share either a bed nor a bedroom due to the level of disability and the aids needed - yet NIHE really interrogate those in receipt of Housing Benefit and push them further into financial difficulty. I know this from personal experience. It has been at least 10 years since NIHE uplifted their Disabled Facilities Grants costings to reflect inflation (pre-Covid)"*
>
> **A disabled person and carer with a long-term health condition**

The Child Poverty Strategy (2016)[315] acknowledges that disability and caring responsibilities can contribute to poverty but provides no mitigating measures beyond those targeted to all families. Proposals are limited and include measures such as access to childcare and uniform grants which are not sufficient to address child poverty. The actions within the Strategy that are associated with disability include grants for providers as opposed to measures targeted to families.

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[315] DFC (2016): The Child Poverty Strategy, p.41 (accessed 4 November 2021).

The benefit freeze, the two-child limit[316] and changes to disability benefits have contributed to reduced levels of financial support for children[317]. The Anti-Poverty Strategy Expert Advisory Panel have recommended an engagement programme targeted towards d/Deaf and disabled people to provide information regarding mitigation strategies and new provision[318]. Despite this recommendation, the Independent Advisory Panel on Welfare Mitigations does not include representation from a DPO[319].

Disability Action, the Northwest Forum of Disabilities and the Independent Advisory Panel on Welfare Mitigations arranged an engagement between d/Deaf and disabled People and the Panel which took place on the 15 December 2021.

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[316] On 6 April 2017, new rules came into force limiting the child element of child tax credit (CTC) and universal credit (UC) awards to two children. This limit only applies to a third or subsequent child born on or after 6 April 2017.

[317] EHRC (2020): The cumulative impact of tax and welfare reforms, pp.15-16 (accessed 3 November 2021).

[318] DfC (2021): Report from the Anti-Poverty Strategy Expert Group, paragraph24, p.8 (accessed 30 October 2021).

[319] DfC (2021): Communities Minister Hargey Commissions welfare mitigations review (accessed 26 December 2021).

The discussion focused upon the following points:

- d/Deaf and disabled people's right to an adequate standard of living and social protection has been seriously eroded as a result of the UK Government's ongoing welfare reform agenda[320];
- families where someone has a disability, have lost an average of £2,000 per year as a result of changes to related benefits;[321]
- reductions in disability benefits have continued from April 2017. Disabled people claiming Employment Support Allowance and Universal Credit, assessed as being in the work-related activity group and in receipt of both benefits through the work capability assessment, have had their income reduced by £30 per week, losing their disability premiums within both benefits[322];
- young people who had previously been allowed contribution-based Employment and Support Allowance (ESA), even if they have not paid national insurance contributions, also lost their entitlement[323];

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[320] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.39 (accessed 10 October 2021).

[321] Northern Ireland Human Rights Commission (November 2019): Cumulative Impact Assessment (CIA) of the Impact by Reforms to the Tax and Social Security System in Northern Ireland, see Section Heading 4.2 Impact by Disability Status of Adults and Children in the Household, pages 53-59 (accessed 5 November 2021).

[322] UK Parliament (2019): Ten Years of the Work Capability Assessment (accessed 18 December 2021).

[323] NI Direct (ND): Changes to Employment and Support Allowance (accessed 18 December 2021).

- those in receipt of contributions-based ESA have had their entitlement to the benefit limited to one year;
- the transfer from Disability Living Allowance (DLA) to PIP and entitlement to the disability elements of Universal Credit (UC) through the work capability assessment has continued using the medical interpretation of disability functional tests to assess entitlement, causing significant stress and anxiety to claimants;
- evidence suggests that d/Deaf and disabled people have no trust in the process according to two independent reviews of the PIP process;
- supporting evidence for PIP claims is not being properly evaluated resulting in unfair decisions being made with regard to entitlement;
- the change of circumstances can result in significant loss in benefit entitlement;
- support to d/Deaf and disabled people on UC during the Covid pandemic of £20 per week on UC has been withdrawn increasing the number of people falling into poverty[324];

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[324] University of Bath (2021): New report reveals hidden complexities of uplift for Universal Credit claimants (accessed 15 December 2021)

- the additional support provided to people on UC was not given to those d/Deaf and disabled people on legacy benefits, those in receipt of Job Seekers Allowance (JSA), Income Support (IS) etc[325];
- the UK Government have been challenged for discriminating against people with mental health issues (psycho-social disabilities) to allow for proper consideration for entitlement to the PIP payment[326];
- d/Deaf and disabled people feel the conditionality and sanctions regime associated with universal credit takes little account of their impairment and they find themselves applying for jobs that do not take into account the nature of their impairment[327];
- there is also some evidence to suggest that d/Deaf and disabled people have not only fallen further into poverty but also lost their lives as a result of welfare reform changes[328];

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[325] Disability News Service (2021): Universal credit uplift failure was 'unfair, unjustified and discriminatory', court hears (accessed 15 December 2021).
[326] CPAG (2018): PIP and Psychological Distress (accessed 15 December 2021).
[327] d/Deaf and Disabled Person's Engagement with the Independent Panel on Welfare Mitigations, chaired by Les Allamby, 15 December 2021.
[328] The Guardian (4 February 2020): Errol Graham is the latest victim of a cruel system – we need a culture shift (accessed 18 December 2021).

- entitlement to PIP, for many, is subject to ongoing assessments every three years on average even where the nature of the impairment is not going to change and d/Deaf and disabled people, in these circumstances, are constantly under stress and anxiety having to undergo repeated assessments even though their circumstances are unlikely to change;
- there is some evidence to suggest that d/Deaf and disabled people who are in work receive PIP awards for a limited period for up to three years. There is no evidence to suggest that consideration is being given to the reasonable adjustments d/Deaf and disabled people receive while in employment when considering PIP award entitlements;

- the current PIP assessment process is viewed with distrust and suspicion. It is a fragmented process that impacts negatively on both claimants and those who seek to support them. The face-to-face assessment causes fear, anxiety, stress, and frustration. This in turn has a knock-on impact on the health and well-being of claimants, their family and wider support networks, placing even more demands on already stretched services[329]. According to the first NI Independent Review of the PIP process, people were being physically sick, having panic attacks, having difficulties with swallowing and breathing during the assessments[330];
- from April 2019 to June 2021 there were 9,999 PIP related appeals lodged in Northern Ireland and of these 5,969 cases (60%) were won by the d/Deaf and disabled claimant[331];
- More than 10 million pounds has been spent by the Department for Communities on the processing these appeals over the last 3 years[332];

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[329] Rader, W. (June 2018): Personal Independent Payment: An Independent Review of the Assessment Process, Executive Summary of Main Findings, p.6.

[330] DfC (2020): Independent Review of the Personal Independence Payment (PIP) Assessment Process in Northern Ireland (accessed 17 December 2021).

[331] DfC (2021): Benefit Statistics Summary Publication (National Statistics) – May 2021 (accessed 5 November 2021).

[332] The Belfast Telegraph (26 July 2021): Over ten Million spent on PIP Appeals over the last three Years (accessed 5 November 2021). Please note the intent of the welfare reforms was to make a 20% saving on disability benefits but in Northern Ireland/UK wide social security spending has increased, partly because of appeals.

- since the introduction of Universal Credit d/Deaf and disabled people considered to have limited capability for work within Universal Credit and Employment Support Allowance but deemed capable under the work capability assessment to undertake work related preparation activities have lost entitlement to a disability premium of £128 per month, £29.05 per week[333];
- since the onset of the Covid-19 pandemic, claimants in receipt of Universal Credit received an additional £20 per week[334]. This increase was not applied to claimants, on legacy benefits such as Income Support and Jobs Seekers Allowance[335].

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[333] DfC (2016): Northern Ireland Universal Credit Information Booklet, p.32 (accessed 5 November 2021).

[334] DfC (2021): Minister Hargey urges DWP to retain £20 Universal Credit uplift (accessed 5 November 2021).

[335] Osbornes/Law (April 2021): High Court challenges the denial of benefit increases for nearly 2 million people with disabilities The high court is to decide whether it was lawful for the government not to give people with disabilities social security benefits the same £1040 a year increase that it has given to all recipients in receipt of universal credit (accessed 5 November 2021).

- The £20 additional payment through Universal Credit was removed on 6 October 2021[336]. This is likely to have a significant impact on over 26,010 households which include adults and children with disabilities on Universal Credit[337];
- sanctions exacerbate the existing illnesses and impairments of d/Deaf and disabled people with particularly negative impacts upon those with mental health conditions[338].

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[336] The Conversation (2021): Universal credit uplift was a lifeline during the pandemic – our research shows cutting it will leave families with impossible decisions (accessed 5 November 2021).

[337] Within Universal Credit there are currently 26,010 households with a working age adult with a disability in receipt of Universal Credit payments that include additional elements of Limited Work Capability and Limited Work Capability work related activity. Both these groups comprise of disabled people and those with long-term health conditions. Those disabled people in the Limited Work Capability receive no additional financial support and are not required to search for employment but must undertake work related activities such as preparing CV's and undertaking training courses while those disabled people in the limited capability for work and limited capability for work related activities do not have to look for work and receive an additional social security benefit of £343 per month. A further 4,270 households that include a disabled child are also in receipt of Universal Credit. Department for Communities (May 2021): NI Universal Credit Supplementary Statistics Tables, See Tables 8a, b and c, Households in Payments with Additional Elements October 2017 – May 2021. Available at: https://www.communities-ni.gov.uk/publications/universal-credit-statistics-may-2021

[338] Dwyer, P., Jones, K., McNeill, J., Scullion, L. and Stewart, A. (2018): Final findings: deaf and disabled people (accessed 3 November 2021).

Participants proposed the following recommendations:

- repeal the PIP benefit and associated assessment for a better alternative, drawing on the human rights based social security legislation in Scotland[339];
- repeal the Work Capability legislation, including the associated assessment and adopt a human rights approach to supporting d/Deaf and disabled people into employment that does not conflict with their right to an adequate standard of living and entitlement to social security;
- the Northern Ireland Government should adopt a human rights-based approach to social security 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;
- maintain and extend the existing welfare mitigations package;

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[339] The Social Security Act (Scotland) 2018 (accessed 26 March 2022).

- 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;
- adopt the recommendations from the British Deaf Association (BDA) for a separate benefit for d/Deaf and disabled people to access language interpretation services;
- retention of the £20 increase for claimants on Universal Credit, to help those on low incomes during the Covid 19 pandemic;
- 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;
- 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
- advance payments to support d/Deaf and disabled people making an initial claim on Universal Credit should be provided in the form of a nonrepayable 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;
- 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[340].

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[340] DfC (2020): Disability Strategy Expert Advisory Panel Report, pp.46-48 (accessed 18 December 2021).

It should be noted that the Chair of the Independent Social Security Mitigations Review Panel, Les Allamby, raised concerns that financial constraints could limit the extent of the review and outlined terms of reference which were narrow in the context of budgetary constraints. The authors of this report note that when this is taken into account, the recommendations of the panel may have limited impact on the lives of d/Deaf and disabled people.

The Anti-Poverty Expert Advisory Panel advised that proposals for weekly non-taxable child payments between £12.50 and £15[341] for disabled children should be extended up to the age of 20 to ensure that families with d/Deaf and disabled children or young people can receive a higher income to support their child in the transition years to adulthood. This report recommends that young d/Deaf and disabled people who have incomes below the poverty line should receive support until they are 24 similar to the provisions within The Family Fund[342].

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[341] Ibid, p.37.

[342] Family Fund (ND): Your Opportunity: Help for 18–24-year-olds (accessed 30 October 2021).

The Family Fund is committed to providing financial support to young people living with disabilities during the transition to adulthood from 18-24, and offers core grants and services to the brothers and sisters of children with disabilities[343].

In January 2021 additional funding of £480,000 was made available by the Department of Health in Northern Ireland, in addition to the £1.57million of annual funding to enable the Family Fund, to provide 5,426 grants to families with essential items in response to the continuing crisis caused by the pandemic (an increase of 1352 families in comparison with the previous year)[344]. The grants focused on providing a range of items including play equipment, tablets, computers, and sensory toys to families with d/Deaf and disabled children[345]. The Family Fund Mobility Support pilot scheme is aimed at providing a discretionary grant to families with disabled children under three years of age, with requirements that the grant should provide additional help to transport equipment such as mobility aids or oxygen supplies related to their condition and should assist families to attend frequent appointments at health centres related to their condition.

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[343] Family Fund (2021): Annual Report and Financial Statements (accessed 30 October 2021).

[344] Ibid, p.14.

[345] Ibid, p.17.

Access to Childcare

ECNI has identified the lack of accessible childcare as a particular issue for parents of d/Deaf and disabled children[346]. Northern Ireland is distinct with respect to other parts of the UK in that the region lacks a childcare strategy. At the time of writing, in contrast with GB[347], no action has been taken with respect to the introduction of a statutory duty upon public authorities to provide adequate childcare for d/Deaf and disabled children with disabilities.

A draft Childcare Strategy, prepared by the Executive, was consulted upon in 2015[348]. There is a commitment within the New Decade, New Approach[349] agreement to deliver extended, affordable, and high-quality provision of early education and care initiatives for families with children aged 3-4. The Minister for Education recently made a commitment to advance the Childcare Strategy[350].

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[346] ECNI (2013): 'Childcare – Maximising the Economic Participation of Women', page 43 (accessed 30 October 2021).

[347] Childcare Act 2006, Section 6 (accessed 30 January 2022).

[348] TEO (2015): Draft Childcare Strategy, (accessed 1 November 2021).

[349] UK Government (2020): New Decade New Approach, p.9 (accessed 1 November 2021).

[350] Belfast Telegraph (2021): McIlveen pledges to bring forward childcare strategy for Northern Ireland, 29 June 2021 (accessed 1 November 2021).

It should be noted that Early Years provision for d/Deaf and disabled children has been reduced by the Education Authority through the move towards the reduction of Early Years provision for children with SEN to 3 hours (dual day)[351]. This decision has been heavily criticised[352]. The report of the Anti-Poverty Strategy Expert Advisory Panel[353] recommends that any future Childcare Strategy must provide childcare that is affordable, accessible, and high quality and that caters for the diversity of the needs of families below the poverty line. The report also recommends that existing Sure Start provision should be expanded, with funding ring fenced to include d/Deaf and disabled children and their families[354].

The Gender Equality Strategy Expert Advisory Panel was appointed in October 2020[355] and was tasked with preparing a report setting out key recommendations to the Minister for Communities, about the themes and key actions the Gender Equality Strategy should include and the gaps in provision that it should seek to address.

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[351] NICCY (2017): Educational Inequalities and Inclusion Paper, p.64 (accessed 30 October 2021).
[352] BBC (2016): Special needs nursery cuts: O'Dowd says decision by Education Authority is 'flawed', 8 March 2016 (accessed 6 December 2021).
[353] DfC (2021): Report from the Anti-Poverty Strategy Expert Group, paragraph19, p.8 (accessed 30 October 2021).
[354] Ibid, paragraph 6.4, p.41.
[355] DfC (2021): Report from the Gender Equality Strategy Expert Advisory Panel (accessed 30 October 2021).

The Panel recommended that childcare provision should be accessible for families with d/Deaf and disabled children. The Panel also recommended that staff within childcare settings should receive cultural competency training to ensure that they are aware of the needs of d/Deaf and disabled children and their families who, in the past, have been marginalised with regard to access to childcare provision[356].

The report of the Anti-Poverty Strategy Expert Advisory Panel[357] noted shortfalls in the implementation of the Children (NI) Order 1995[358], pointing out that the duties mandated in Sections 17 and 18 of the Order for the provision of personal and social services for families of d/Deaf and disabled children "in need" had not been fulfilled by local Health and Social Care Trusts. The Panel recommended that shortfalls in the implementation of the 1995 Order should be reviewed and acted upon and that a wide range of policy interventions should be made to support and recognise children in poverty.

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[356] DfC (2021): Report from the Gender Equality Strategy Expert Advisory Panel. paragraph 3.6.4, p.62 (accessed 30 October 2021).

[357] DfC (2021): Report from the Anti-Poverty Strategy Expert Group' p42 (accessed 30 October 2021).

[358] The Children (Northern Ireland) Order 1995

Most of these recommendations simply named issues that children and young d/Deaf and disabled people might face such as ‘rural isolation...bullying...violence within the home and hate crime’[359] without outlining the related interventions to be included in anti-poverty strategy. However, the Panel did make substantial recommendations in the area of additional benefits, including consideration of measures to establish a winter fuel allowance for families with disabilities and a review of the core eligibility criteria for the Warm Home Discount to ensure support is targeted toward d/Deaf and disabled people who face extra heating costs due to immobility[360].

Intersectionality

The Disability Strategy Expert Advisory Panel report emphasised the importance of intersectionality and the lived experience of disabilities[361] but noted that consideration of these issues appears to have fallen between policy which addresses the needs of children and young people generally (and which has not adequately addressed disability) and disability policy which has focuses upon adults (with little attention paid to the needs of d/Deaf and disabled children).

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[359] Ibid, p.43.

[360] Ibid, paragraph 6.9, p.43.

[361] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.108 (accessed 10 October 2021).

Children and Young People's Strategy

The Northern Ireland Children and Young People's Strategy 2020-2030 (January 2021)[362] made a commitment to take the UNCRPD into account in policy making aimed at improving services for young deaf and d/Deaf and disabled people. The Strategy does not contain any detailed measures that can be implemented for the benefit of d/Deaf and disabled children.

The Strategy references the existence of the current legislative framework with no recommendations for enhancement. Some reference is made to the health[363] and play[364] needs of children with disabilities. There is no acknowledgement of the need to hear the voice of children with disabilities. The Strategy acknowledges that children d/Deaf and disabled children should have access to special care and support to lead full and independent lives. It is acknowledged that d/Deaf and disabled children and children with complex needs should be properly supported[365].

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[362] NI Executive (2021): Children and Young People's Strategy, paragraph 4.2, p. 16 (accessed 30 October 2021).

[363] Ibid, paragraph 6.33, pp 45-46.

[364] Ibid, paragraph 6.20, p.38.

[365] NI Executive (2021): Children and Young People's Strategy, paragraph 6.2, p. 38 (accessed 30 October 2021).

The Strategy commits to collaborative working, early identification, diagnosis, help, support and intervention, better collaboration between health and education, joined up services, greater awareness of the need for suitable play and leisure activities, improved information, the provision of appropriate support and ensuring the needs of children with disabilities are included in policies and strategies. The Strategy does not identify a clear mechanism through which this will be achieved[366].

Hate Crime and Hate Speech

At the time of writing, no actions had been taken to address hate crime or hate speech directed at children and young people with disabilities. Participants in the research to inform this study told us of their experiences of bullying and the isolation and distress which this caused them:

> *"There's very limited support for kids and their rights and they're being stretched to their limits. There are not enough adequate schools to support their education, participating in certain sports. Being bullied because you're different from your peers, feelings of isolation plus severe levels off anxiety".*

Disabled woman carer with long-term health condition 40-44.

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[366] Ibid, paragraph 6.23, p.40.

Mental Health

The NI Commissioner for Children and Young People's (2018) report 'Still Waiting' raises serious concerns about the accessibility of Child and Adolescent Mental Health Services by young people with learning disabilities[367]. The Disability Strategy Expert Advisory Panel have proposed several measures in response:

1. a comprehensive and integrated mental health service model for disabled children and young people across Northern Ireland should be agreed and implemented. This model must ensure that young people with a disability can access comparable services and support as young people without a disability;
2. a comprehensive review of community based emotional, mental, and behavioural support services for and young people with a disability and with learning disabilities should be undertaken;
3. the Department of Health should assess the extent to which Children and Adolescent Mental Health Services (CAMHS) is accessible for children and young people with a disability including the provision of sign language for children who require it[368].

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[367] 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, p.14, Belfast: NICCY.

[368] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.115 (accessed 10 October 2021).

Autism Act and Strategy

The Autism Act (NI) 2011, Action Plan and Strategy raised the hopes of autistic people and their families[369]. The Autism Act (NI) 2011, covered two areas for development. First, it required changes to the Disability Discrimination Act 1995 to include people with autism, making it clear that 'a condition which has a substantial and long-term adverse effect on someone's ability to take part in normal social interaction or in forming social relationships can constitute a disability'[370]. Second, the Act required the Executive to implement a cross-departmental Autism Strategy which outlines how the health, educational and social needs of people with autism will be addressed across the lifespan. It must also set out how families' and carers' needs will be addressed and develop an autism awareness campaign[371].

A multi-disciplinary Regional Autistic Spectrum Disorder Network (RASDN) was set up to take the plan forward, and began work in April 2009[372]

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[369] Autism NI (2016): Broken Promises, p.4 (accessed 14 December 2021).
[370] Autism Act (Northern Ireland) 2011 (c. 27 (N.I.) , ss. 1(2), 5; Disability Discrimination Act 1993, Schedule 1, paragraph 4.1: i-j (accessed 12 December 2021).
[371] Autism Act (NI) (2011) 2 (accessed 12 December 2021).
[372] HSCB (2010): Regional Autistic Spectrum Disorder Network (RASDN) (accessed 12 December 2021).

An update to the Autism Strategy, with a second action plan, was put in place in 2014[373] which set out eleven themes:

- awareness;
- accessibility;
- children, young people, and family;
- health and wellbeing;
- education;
- transitions;
- employability;
- independence, choice, and control;
- access to justice;
- being part of the community;
- participation and active citizenship[374].

Despite the Act and Action Plan being initially welcomed by autistic children, adults, and families, a sense of frustration emerged in the context of the uneven impact of the legislation and Action Plan. Concerns were raised that provision had deteriorated rather than improved[375].

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[373] DoH (2014): Autism strategy and action plan (accessed 12 December 2021).
[374] Ibid, p.10-11.
[375] Autism NI (2016): Broken Promises, p.6 (accessed 14 December 2021).

In October 2020, the Minister of Health, Robin Swann MLA, confirmed that he had intended to publish a revised Autism strategy at the beginning of 2021, but this has been delayed due to COVID-19[376]. Participants in the qualitative research informing this study shared their concerns regarding the mental health challenges experienced by autistic children:

> "*Expecting teachers to identify and distinguish autistic traits compared to other behaviours is horrendous. Educational psychologists should be employed to assess ALL children, not just those identified by underpaid teaching staff. Autistic girls in particular suffer severe bullying and mental health problems in later life due to the negative experiences they have in mainstream schools.*
>
> *It is punishment forcing children into noisy busy environments, whose condition means they are unable to cope there. More needs done to include autistic girls in inclusive education. Especially specific training to identify their camouflaged traits.*

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[376] NI Assembly Hansard, 'Response to Written Question – Autism Strategy – Robin Swann MLA – AQW 6252/17-22', 5 October 2020.

> *The removal of autism from the special educational needs register is a cruel decision made by the Education Authority in Northern Ireland. Parent carers of autistic children are voicing their stresses and concerns for their children's mental health and wellbeing as they are forced into these busy environments and coming home from school a shell of themselves due to bullying and environments which are terrifying for them. Consideration should be given to the distinct needs of autistic children and proper provision provided for them."*
>
> **A non-disabled woman carer aged 40-44**

Autism NI published 'Broken Promises' in 2016, which highlighted that 35% of autistic adults and 46% of family members felt that support for autistic adults and children had deteriorated in the 3 years preceding the publishing of the report[377]. Two thirds of those who participated in the research underpinning the report indicated that there was not enough support for parents and carers[378]. The report called on the Executive and the Assembly to:

- ensure that the Autism Strategy and first Action Plan are fully implemented;

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[377] Autism NI (2016): Broken Promises, p.4 (accessed 14 December 2021).
[378] Ibid.

- put in place independent scrutiny and monitoring of the Autism Strategy and Action Plan;
- involve and consult autistic people, parents/ carers, and the autism sector in the development of the new Autism Action Plan, its monitoring and implementation;
- implement a thorough review of autism funding required across departments to address the existing funding gap, taking into account the emerging data on autism from Health and Education;
- make sure the welcome new funds for diagnosis for children reach the front line – and evaluate the impact of this funding on waiting times;
- report on diagnosis times and invest in diagnostic services for adults – they are just as important as those for children;
- create a new funding pool to enable the development of new services for autistic adults, children, and their carers;
- create a record of all unmet need that is outlined in carers' assessments and needs assessments and use it to inform the commissioning of services;
- ensure that carers of autistic children and adults receive the respite they need, when they need it invest and expand the range of respite services in Northern Ireland for carers of autistic people;

- examine the data showing the type of autism specific provision that parents would like their children to receive and invest in at least one autism-specific school in Northern Ireland so there is genuine choice within the system;
- ensure that students in further education can use their Disabled Students' Allowance to access their own autism-specific support, if wanted;
- undertake an independent examination of the range of support provided to autistic young people/adults to examine if it meets their needs;
- ensure that autistic adults can access a range of autism-specific pre- and post-employment support that best meets their individual needs;
- devise and implement an awareness raising campaign aimed at employers to increase their understanding of autism and help create real jobs for autistic adults;
- ensure the Northern Ireland Assembly, Government Departments and associate agencies show leadership by monitoring the number of autistic people they employ and proactively examining their recruitment policies to ensure equal access;

- fulfil the requirement under the Autism Act and secure funding to develop a public awareness campaign on autism that will promote real understanding;
- require government departments and associated agencies to instigate a programme of training in serving autistic people and sign up for autism-friendly or similar awards.[379]

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[379] Ibid, pp.4-5.

Families from disadvantaged backgrounds face various challenges to participating in intervention programmes which is reflected in their lower uptake and higher drop-out rates[380]. It was against this background that the Reaching Autism Families Together (RAFT) was conceived by Autism NI, the principal voluntary organisation working for persons with autism in Northern Ireland. This involved Autism NI partnering with one of the five Health and Social Care (HSC) Trusts which undertake the assessment and diagnosis of children with autism spectrum disorder (ASD). The Autism NI Reaching Families Together Project funded by the Big Lottery[381] demonstrated the importance of parental support to families with children with autism. The evaluations suggested that a brief home-based intervention is a viable and effective means of providing personalized, post-diagnostic support to parents at periodic intervals, although socially disadvantaged families may require additional assistance beyond managing their child's ASD. The project also highlighted broader issues that impede effective support for families[382].

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[380] Haine-Schlagel, R. and Walsh, N.E. (2015): A Review of Parent Participation Engagement in Child and Family Mental Health Treatment, *Clinical Child and Family Psychological Review* 18, pp. 133–150.

[381] Autism NI (ND): Reaching Autism Families Together (RAFT) An Autism Specific Early Intervention Research Model in Practice 2015-2020 (accessed 26 December 2021).

[382] Mullan, A., Boyd, K. and McConkey, R. (2021): The Impact of a Brief Home-Based Intervention on Families with a Child with Autism Spectrum Disorder, *Journal of Developmental and Physical Disabilities* 33**,** pp 693–708.

The overall aim of the RAFT project was to build and strengthen relationships for families of children diagnosed with ASD aged 12 and under. In particular, the main objectives were:

- to equip families with the knowledge and skills to address the difficulties their child was currently experiencing;
- to enable the children and families to experience a better quality of home life;
- to reduce the social isolation children and families experience and promote increased levels of community connectedness[383].

Over the four years when the project was fully operational, 456 children participated, 85% of the 534 children referred to it. In all, 48 parents (9%) declined the offer of a place, 26 (5%) dropped out with only three (0.6%) inappropriate referrals on account of age. Among the 456 participating children, there were 56 siblings in 29 families. Thus 427 families had participated[384]. The proportion of families living in areas of social deprivation was ascertained using the Multiple Deprivation Measures for Northern Ireland (NISRA 2017). The latter ranks districts in terms of the centiles of deprivations.

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[383] Autism NI (ND): Reaching Autism Families Together (RAFT) An Autism Specific Early Intervention Research Model in Practice 2015-2020 (accessed 26 December 2021).

[384] Ibid.

In all, 20% of families resided in the top 20 % of areas in Northern Ireland with the highest levels of social deprivation whereas 34% lived in the 20 % of areas that were least deprived. By comparison, for the HSC Trust as a whole, 13% lived in the most deprived areas and 18% in the least deprived areas[385]. A higher percentage of the 30 families who declined to participate or who dropped out of the project lived in the most deprived areas (43%) compared to 20% in the least deprived areas who participated in the project (Chi Sq 5.64: $p < 0.05$)[386].

The children mostly attended mainstream schools, but the families reported often having no access to advice and guidance to cope with the issues the child with ASD presented at home. Only a small minority of families were receiving therapy, with few having access to specialist programmes to address autism[387]. More than half the children had waited over 12 months for personalised, post-diagnostic support. The delay is compounded by the increased numbers of children being diagnosed which resulted in longer waiting times for access to post-diagnostic support.

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[385] Ibid.
[386] Ibid.
[387] Ibid.

One solution would have been to increase the resources available for the provision of post-diagnostic support; yet health and social care funds seemed to be targeted mainly at assessment services which, in this instance, resulted in the termination of the project despite the evidence of its impact on families[388].

The first reading of an Autism Private Members Bill took place on 5 July 2021. The Bill, sponsored by Pam Cameron MLA, seeks to strengthen the current Autism Act (NI) 2011 and addresses the need for better provision of children and adult autism services by introducing an independent scrutiny mechanism to drive forward the regional implementation of autism services. The public consultation process on the Bill attracted more than 1,800 responses in October 2020, receiving more responses than any other legislative consultation within the NI Assembly[389].

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[388] Ibid.

[389] Autism NI (2021): First reading of Autism Private Members Bill (accessed 20 October 2021).

Access to Play and Leisure

From a rights-based perspective, all children have a right to play, rest and leisure under Article 31 of the Convention. Children with disabilities are frequently excluded from play, in particular from accessing and using outdoor play spaces, denying them their full enjoyment of their rights. Thus, play provision becomes an issue of social in/exclusion and social support[390].

Outdoor play has a significant role in children's general health and well-being, partly because of the connection with nature, which strongly impacts on physical and mental health of children, especially when allowed to play freely[391]. Whilst there has been some improvement in access to accessible play opportunities in areas including the Mo Mowlam Play Park[392] and Diversity Park in Portstewart[393] there continues to be a lack of play and leisure opportunities for children and young disabled people due to a lack of inclusive and accessible mainstream activities.

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[390] Children's Research Network (2017): Playspaces: Children with disabilities and social inclusion (accessed 26 December 2021).

[391] Gill, T. (2014): The Benefits of Children's Engagement with Nature: A Systematic Literature Review, *Children, Youth and Environments*, *24*(2), pp 10–34.

[392] NI Executive (2019): Inclusive playpark opens ahead of summer holidays.

[393] Fields in Trust (2021): Universality of Parks: Diversity Park - a playground for children of all abilities (accessed 26 December 2021).

For example, access to playgrounds with accessible equipment is limited, despite some investment by local authorities. The “Are Play Spaces Accessible to All?”[394] reported that almost a third of families travelled up to an hour and a half out of their council areas to access suitable fixed play provision.

Changing Places

There continues to be an absence of suitable toilet and changing facilities for families with d/Deaf and disabled children and young people[395]. The “Are Play Spaces Accessible to All” study reports that 50% of respondents participating require access to a Changing Places Toilet reported challenges in accessing facilities. The absence of suitable toilets means that d/deaf and disabled people who require access to Changing Places cannot take part in activities such as shopping, going out for a meal or attending a sporting event. Without a suitable changing bench and hoist, many people with complex needs have to be laid on unhygienic toilet floors or become trapped in their own homes.

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[394] Mae Murray Foundation (2020): Are Play Spaces Accessible to All? (accessed 26 December 2021).

[395] Ibid.

The campaign by Changing Places to see more toilets with large changing areas and hoists shows the real-life problems faced by people who need support to use the toilet or to change continence pads[396]. The Department of Finance launched a consultation to introduce requirements for the fitting of a Changing Places Toilet in certain buildings commonly used by the public[397].

Human Rights Model

The Northern Ireland NGO Stakeholder Report (2020)[398], to inform the UN Committee on the Rights of the Child 's consideration of a list of issues, documents historic shortfalls with respect to the human rights model of disability and the absence of data or monitoring mechanisms to assist the development and evaluation of policy. The report notes a significant lack of data relating to the experience of d/Deaf and disabled children and young people who require sign language.

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[396] Jones, C., Slater, J., Cleasby, S., Kemp, G., Lisney, E. and Rennie, S. (2019): Pissed Off! London: Routledge.

[397] DoF (2021): Murphy launches consultation to mandate Changing Places Toilet provision in Building Regulations (accessed 26 December 2021).

[398] Children's Law Centre (2020): NI NGO Stakeholder Report to Inform the UN Committee on the Rights of the Child: List of Issues Prior to Reporting, p.18 (accessed 20 October 2021).

The report also highlights the impact of discrimination on the mental health and wellbeing of children and young people with a learning disability. There are challenges associated with ensuring that d/Deaf and disabled children have the right to express their views on matters which affect them. There is a lack of statistics and evidence regarding the lived experience of d/Deaf and disabled children available to policymakers. There is a lack of information available with respect to the number of families with disabled children as well as challenges in identifying and assessing poverty levels within these families. The additional costs of disability can be difficult to quantify; and disability benefits continue to be treated as disposable income when measuring poverty levels within official statistics[399].

The Disability Strategy Expert Advisory Panel report identifies a range of barriers that d/Deaf and disabled children experience including the attainment gap between children with and SEN, barriers in accessing essential support services, the challenges in the delivery of SEN, informal exclusions, and segregation [400].

Recommendations from the Anti-Poverty Expert Advisory Panel with respect to addressing poverty include:

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[399] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations. p.110 (accessed 10 October 2021).

[400] Ibid, p.93.

- proposals for weekly non-taxable child payments between £12.50 and £15[401] for disabled children to be extended up to the age of 20 to ensure that families with d/Deaf and disabled children or young people can receive a higher income to support their child in the transition years to adulthood. This report recommends that young deaf and disabled people who have incomes below the poverty line should receive support until they are 24 years old, similar to the provisions within The Family Fund[402];
- the Childcare Strategy must provide childcare that is affordable, accessible, and high quality and that caters for the diversity of the needs of families below the poverty line. The report also recommends that existing Sure Start provision be expanded, with funding ring fenced to include d/Deaf and disabled children and their families[403];
- shortfalls in the implementation of the Children Order (1995)[404] should be reviewed and acted upon and that a wide range of policy interventions should be made to support children in poverty;[405]

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[401] Ibid, p.37.
[402] Family Fund (No date): Your Opportunity: Help for 18–24-year-olds, (accessed 30 October 2021).
[403] Ibid, 6.4, p.41.
[404] The Children (Northern Ireland) Order 1995 (accessed 31 January 2022)
[405] Ibid, p.43.

- substantial recommendations in the area of additional benefits, including consideration of measures to establish a winter fuel allowance for families with disabilities and a review of the core eligibility criteria for the Warm Home Discount to ensure support is targeted toward deaf and disabled people who face extra heating costs due to immobility[406].

Recommendations from the Gender Equality Expert Advisory Panel include that:

- childcare provision should be accessible for families with d/Deaf and disabled children;
- staff within childcare settings should receive cultural competency training to ensure that they are aware of the needs of d/Deaf and disabled children and their families who, in the past, have been marginalised regarding access to childcare provision[407].

The Disability Strategy Expert Advisory Panel proposed the following measures[408]:

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

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[406] Ibid, paragraph 6.9, p.43.

[407] DfC (2021): Report from the Gender Equality Strategy Expert Advisory Panel, paragraph 3.6.4, p.62 (accessed 30 October 2021).

[408] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, pp.115-116 (accessed 10 October 2021).

- take forward the following four recommendations from the Northern Ireland Commissioner for Children and Young People (NICCY) (2018) 'Still Waiting' report[409]:
    1. a comprehensive and integrated mental health service model across Northern Ireland for disabled children should be agreed and implemented. This model must ensure that young people with a disability can access comparable services and support as young people without a disability;
    2. 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;
    3. a comprehensive review of community based emotional, mental, and behavioural support services for young d/Deaf and disabled people and young people with learning disabilities should be undertaken;
    4. 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;

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[409] NICCY (2018): Still Waiting, pp. 37-40 (accessed 31 January 2022).

- 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;
- actions is required to collect and resource the collection of data on the numbers of d/Deaf and disabled children in Northern Ireland in line with UNCRPD rights-based indicators;
- build on the Children and Young People's Strategy by ensuring that a new Disability Strategy develops a rights- based comprehensive action plan for the full and meaningful inclusion of d/Deaf and disabled children;
- ensure the Anti-Poverty Strategy is inclusive of families with d/Deaf and disabled children and takes account of extra costs of disability, excluding disability benefits from income when assessing disability poverty in family settings;
- provide adjusted measures 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 by coordinating legislation, policy and programmes across relevant sectors and ensure fully informed decisions by children with disabilities are respected, with personal choice reflected by involving them in the design of services and by providing advice and information on available options;
- ensure d/Deaf and disabled children are supported via financial investment and personal interaction to express their views and have their views given due weight in all decision making that affects them;
- 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.

The authors of this report recommend:

- an integrated strategy which is appropriately resourced to advance inclusive play across the region;
- an investment programme and strategy to deliver adequate provision of Changing Places toilets across the region;
  delivery of investment to support a short breaks and respite strategy for d/Deaf and disabled children, their families and carers which is adequately resourced and includes suitable and sustainable provision.

Autism NI's 'Broken Promises' report (2016) proposed the following recommendations:

- ensure that the Autism Strategy and Action Plan are fully implemented;
- put in place independent scrutiny and monitoring of the Autism Strategy and Action Plan;
- involve and consult autistic people, parents/ carers, and the autism sector in the development of the new Autism Action Plan, its monitoring and implementation;

- implement a thorough review of autism funding required across Departments to address the existing funding gap, taking into account the emerging data on autism from Health and Education;
- make sure funds for diagnosis for children reach the front line – and evaluate the impact of this funding on waiting times;
- report on diagnosis times and invest in diagnostic services for adults – they are just as important as those for children;
- create a new funding pool to enable the development of new services for autistic adults, children, and their carers;
- create a record of all unmet need that is outlined in carers' assessments and needs assessments and use it to inform the commissioning of services;
- ensure that carers of autistic children and adults receive the respite they need, when they need it, invest and expand the range of respite services in Northern Ireland for carers of autistic people;
- examine the data showing the type of autism specific provision that parents would like their children to receive and invest in at least one autism-specific school in Northern Ireland so there is genuine choice within the system;

- ensure that students in further education can use their Disabled Students' Allowance to access their own autism-specific support, if wanted;
- undertake an independent examination of the range of support provided to autistic young people/adults to examine if it meets their needs;
- ensure that autistic adults can access a range of autism-specific pre- and post-employment support that best meets their individual needs;
- devise and implement an awareness raising campaign aimed at employers to increase their understanding of autism and help create real jobs for autistic adults;
- ensure the Northern Ireland Assembly, government departments and associate agencies show leadership by monitoring the number of autistic people they employ and proactively examining their recruitment policies to ensure equal access;
- fulfil the requirement under the Autism Act and secure funding to develop a public awareness campaign on autism that will promote real understanding;

- require government departments and associated agencies to instigate a programme of training in serving autistic people and sign up for autism-friendly or similar awards.[410]

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[410] Ibid, p.4-5.

Article 8: Awareness Raising

> *"I am aware that there are bodies to protect disabled people from overt abuse or discrimination. However, it is often covert discrimination that I face day to day. Until society changes its attitude towards disabled people it is my fear things shall stay this way".*
>
> **Disabled woman with long-term health condition, 16-24.**

Article 8 places an obligation on the State to undertake immediate and effective measures to raise awareness with the objective of engendering the rights and dignity of d/Deaf and disabled people[411]. The UNCRPD Committee has expressed concerns regarding the persistence of prejudice and stereotypes with respect to disabilities. The Committee has recommended that the State Party works closely with DPOs to develop and strengthen awareness raising campaigns with the overall aim of eliminating negative stereotypes and prejudice towards people with disabilities.

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[411] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 8 (accessed 4 November 2021).

The Committee have recommended that the State Party develop mass media campaigns and strategies based on the human rights model of disabilities with the aim of targeting different audience groups[412]. The Public Health Agency (PHA) hosted an awareness campaign on the theme of hidden disabilities as part of Celebrate Disability Awareness Week in 2020[413].

A recent review of Disability Action Plans[414] produced by Executive Departments highlights a number of action measures intended to promote awareness of disabled people, for example, the Department for the Economy's Disability Action Plan commits to an action measure[415] to deliver Autism Awareness Training from 2013-2020 as well as producing an Autism Factsheet. While the Department for Education commits to promoting greater awareness of the Mental Health Charter.

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[412] 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, paragraphs 22 and 23.

[413] Public Health Agency (2020): PHA launches virtual Disability Week NI programme (accessed 2 January 2022).

[414] ECNI (2007): A Guide for Public Authorities – Promoting positive Attitudes Towards Disabled People and Encouraging the Participation of Disabled People in Public Life The Disability Discrimination Act 1995 (as amended) requires that Public Authorities when carrying out their functions must have due regard to promoting positive attitudes towards disabled people. Public Authorities are required to prepare Disability Action Plans detailing action measures how they will achieve this and includes, for example, measures to portray (and encouraging others to portray) disabled people in a positive role as well as taking steps to eliminate ignorance and prejudice towards disabled people in the wider community and the workplace

[415] ECNI (2020): Disability Action Plan Example Action Measures (see Section 1, (2), pp. 4-5 Measures to promote positive attitudes amongst employees, office holders and others (such as the wider public, customers, service users, students etc.

Hate crimes against d/Deaf and disabled people increased from 63 in 2018-19 to 86 in 2019-20[416]. 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[417]. Judge Desmond Marrinan was appointed by the Department of Justice to carry out an independent review of hate crime legislation in 2019[418]. The review is considered within this report under Article 13 Access to Justice.

There is persistent prejudice towards d/Deaf and disabled people, including negative attitudes towards d/Deaf and disabled people claiming social security benefits[419]. Participants in the qualitative research to inform this study have told us that they feel forgotten, looked down on and under-valued:

> "*We are looked down on, belittled, not given the same opportunities as others, and treated like children, under looked an undervalued".*
>
> **Disabled woman with a long-term health condition aged 30-34.**

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[416] PSNI (2021): Incidents and Crimes with a Hate Motivation Recorded by the PSNI: Update 30th June 2021 (accessed 4 November 2021).

[417] UK Independent Mechanism Parallel: Report to the CRPD Committee (2017) Disability rights in the UK, p. 44.

[418] DoJ (2019): Review of Hate Crime Legislation launched (accessed 11 December 2021).

[419] Morris, R (2012): The impact on disabled people of cuts and changes in benefits and services, p.21 (accessed 4 November 2021).

Further measures are needed to raise awareness and combat negative attitudes to meet UNCRPD requirements. d/Deaf and disabled people engaging with Disability Action have been vocal on the need for action to increase awareness of disability rights, to combat stereotypes and to assist in tackling prejudice[420]. At the time of writing there is no co-ordinated strategy to raise awareness of the diverse experience of disability within NI.

There is a particular need to challenge and address negative stereotypes of people with disabilities by the general public, including negative perceptions of children with disabilities. Awareness-raising is a theme in the previous Disability Strategy 2012-2015[421], and in the Interim Autism Strategy[422]. Yet there is little evidence of a strategy through which to advance awareness of resources or of a budget for this activity. While commitments have been made to awareness raising, there is no evidence of a co-ordinated strategy[423].

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[420] Disability Action Research Focus Groups 2021.

[421] TEO (2013): Disability Strategy 2012 – 2015 Baseline Indicator Set, p.4 (accessed 21 December 2021).

[422] DoH (2021): Autism – Interim Strategy 2021-2022, fig 2, p.9 (accessed 21 December 2021).

[423] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, paragraph 2.7, p.27 (accessed 12 December 2021).

Participants in the qualitative research which informs this study told us that they face constant discrimination and are viewed as a burden on society:

> "*There are still people in NI who look down on others who have disabilities, both hidden and visible. There is an attitude in NI that people who don't have disabilities are more capable than those who do, and this is unfair and discriminatory".*
>
> ***Disabled woman, carer and representative of a DPO***

Training programmes or awareness-raising strategies should be developed in conjunction with people with disabilities. Education and training on the UNCRPD are required. It is not clear what impact any existing awareness raising programmes have had, at the time of writing, there was no evaluative overview of the impact of either training or awareness raising programmes by public authorities in the public domain.

The Disability Strategy Expert Advisory Panel recommended the following actions:

- 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 curricula[424].

The authors of this report propose the following additional recommendations:

- awareness raising needs to be much more systematic
- awareness-training programmes should be developed which raise awareness of the rights of d/Deaf and disabled people for d/Deaf and disabled people;
- d/Deaf and disabled people should be at the heart of awareness raising strategies and programmes.

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[424] Ibid, p.28.

Article 9: Accessibility

> *"Sometimes I wait at bus stop in my wheelchair quite often bus just goes on by leaving me just sitting there I was once asked to leave a shop because my chair was pushing against boxes in the aisles United Nations nor govt will ever change these things as there is time and money issues and they are more important than disabled people"* **Disabled man, aged 65+.**

Article 9(2) of the Convention requires that the Executive both identifies and eliminates obstacles and barriers to accessibility with respect to buildings, roads, transportation, and other indoor and outdoor facilities, including schools, housing, medical facilities, and workplaces; and information, communications, and other services, including electronic services and emergency services.

The UNCRPD 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, shopping establishments, postal, banking, communication and information services[425].

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[425] UNCRPD (2014): General Comment No. 2 Article 9: Accessibility, paragraph 17 b, p.6 (accessed 12 December 2021).

Article 9(2) stipulates the measures States parties must take to develop and monitor the implementation of minimum national standards for the accessibility of facilities and services[426].

The UNCRPD Committee has raised concerns, in its concluding observations, regarding the insufficient scope, content and number of obligatory and implemented accessible standards relating to amongst others, the physical environment, affordable housing, information and communications technology (ICT), transport and information in urban and rural areas. It is also concerned that austerity measures have hindered the advancement of accessibility for persons with disabilities.

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[426] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 9 (accessed 4 November 2021).

The Committee has recommended that the NI Executive works in close collaboration with DPOs to identify gaps in the Executive's approach to obligatory accessibility standards in all areas; to pay attention to the links between article 9 of the Convention and the Committee 's General Comment No. 2 (2014) on accessibility and targets 9, 11.2 and 11.7 of the Sustainable Development Goals; and to monitor developments towards full inclusion through accessibility; and sanction violations of accessibility regulations[427].

In its General Comment No.2 on accessibility[428], the UNCRPD Committee specified that denial of access should be considered to constitute a discriminatory act and that the right to access is to be ensured through the strict implementation of accessibility standards. Accessibility is essential to ensure inclusion and to promote independence[429]. Without accessibility d/Deaf and disabled people cannot fully participate in society.

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[427] 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, paragraphs 24 and 25 (accessed 3 November 2021).

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

[429] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.72 (accessed 10 October 2021).

Despite some improvements, d/Deaf and disabled people continue to face difficulties in accessing appropriate housing, the built environment, public transport, services, and information[430].

Article 9[431] states that access to transport is critical if people with disabilities are to live independently and participate in all aspects of life. The lack of access to transport is a persistent challenge which can limit the access of d/Deaf and disabled people to education, health, employment and independent living and results in excluding and marginalising deaf and disabled people.

The participants in the qualitative research which informs this report have told us of the significant barriers which they face in accessing transport and the impact that this has on their right to independent living:

> *"All the transportation systems in N. Ireland are horrendous. You can't get taxis that will take an electric wheelchair. There is no adequate transport after about 4:00 pm. It's like living under curfew".*
>
> **Disabled person with long-term health condition aged 55-59.**

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[430] Ibid, 74.

[431] UNCRPD (2014): General Comment No. 2 Article 9: Accessibility, paragraph 17 b, p.6 (accessed 12 December 2021).

Research has indicated that d/Deaf and disabled people experience significant barriers in accessing transport with respect to both physical accessibility and availability of service[432]. There are challenges with respect to disability awareness amongst staff employed by transport companies[433]. Whilst there have been some improvements[434] in recent years to transport infrastructure, these are largely within the greater Belfast area and inequalities in access persist in other parts of the region[435].

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[432] Harper, C., McClenahan, S., Byrne, B. and Russell, H. (2012): Disability Programmes and Policies how does Northern Ireland measure up?, p.106 (accessed 10 October 2021).

[433] IMNI (2017): United Nations Convention on the Rights of Persons with Disabilities Jurisdictional 'Parallel' Report on Implementation in Northern Ireland: Working Paper, p.22 (accessed 2 November 2021).

[434] Improvements in transport infrastructure include:

- The Disability Action Transport Scheme for people living in towns and cities who find it difficult to use public transport;
- Translink Easibus services which are mainly operational in Belfast provide accessible local bus services for (but not exclusively to d/Deaf and disabled people and older people);
- Shopmobility provides financial support for schemes in Ballymena, Belfast, Carrickfergus, Cookstown, Dungannon, Enniskillen, Lisburn, Derry/Londonderry (known as Foyle), Magherafelt, Newry and Omagh. These schemes lend manual and powered wheelchairs and powered scooters to members of the public with limited mobility to shop and use leisure and commercial facilities.

[435] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.78 (accessed 10 October 2021).

There are ongoing challenges concerning public transport associated with service costs, provision, and timetabling[436], resulting in disabled people having no choice but to access costly private solutions. Participants in the qualitative study which informs this report have been vocal regarding the barriers they face in accessing both public and private transport. Participants have raised the importance of co-designing services with d/Deaf and disabled people to ensure that service are actually accessible:

> "*It is difficult to actually get accessible transport, there is no room on buses, and they don't always come at a suitable place, making somewhere accessible isn't always accessible as a disabled person isn't asked what is needed"*
>
> **Disabled woman aged 60-64.**

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[436] Harper, C., McClenahan, S., Byrne, B. and Russell, H. (2012): Disability Programmes and Policies how does Northern Ireland measure up? pp.165-186 (accessed 10 October 2021).

The Inclusive Mobility Transport Advisory Committee (IMTAC) is an organisation of and for d/Deaf and disabled people and older people, as well as key transport professionals, funded and supported by the Department for Infrastructure. In December 2020 IMTAC expressed concerns that Translink[437] are continuing to invest in high-floor buses which are inaccessible to many disabled people against IMTAC advice. IMTAC have consistently advised against the purchase of high-floor buses for 7 years.[438]

Access remains an issue in many rural parts of Northern Ireland. d/Deaf and disabled people living in rural areas can face considerable challenges in accessing transport[439]. Budget cuts to public services including accessible and affordable community transport in urban and rural areas undermine the priority that should be given to making independent living a reality for all d/Deaf and deaf and disabled people[440].

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[437] The main public transport company in Northern Ireland.

[438] IMTAC (2020): Comments on Proposals for 2020 Translink Goldline Vehicle (buses) Procurement (accessed 3 January 2022).

[439] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.79 (accessed 10 October 2021).

[440] IMTAC (2019): IMTAC Annual Report, p.9 (accessed 12 December 2021).

d/Deaf and disabled people also face challenges due to inaccessible pedestrian environments which can restrict access to local services and facilities including transport and other opportunities. Challenges include the overuse of street furniture[441], pavement advertising and vehicle parking on pavements[442].

The participants in the qualitative research which informs this report told us that pavements are inaccessible for many disabled people:

> *“Every time my husband who is wheelchair bound goes out there are barriers - cars parked on footpaths, not all footpaths have drop down kerbs; shops have so many cabinets and shelving that he can't access the actual shop*
>
> **Non-disabled woman carer aged 60-64.**

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[441] The use of street furniture has increased in the context of the pandemic as outside hospitality has been encouraged in the context of public health.

[442] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.79 (accessed 10 October 2021).

Nichola Mallon, MLA and Minister for Infrastructure recently launched a public awareness campaign regarding the dangers of pavement parking. The campaign forms part of the Department for Infrastructure behavioural change programme which aims to influence the choices drivers make when choosing where to park[443].

There are ongoing challenges with respect to the accessibility of information[444]. There is currently no approach in place to monitor the accessibility of physical or communication environments.

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[443] DfI (2021): Pavement Parking – Mallon urges drivers to "Think Before You Park" (accessed 1 November 2021).

[444] Ibid, p.74.

The Minister for Infrastructure, Nichola Mallon has signalled her intention to extend the Concessionary Fares Scheme[445]. The current Scheme provides free and half fare travel on public transport, via a SmartPass, for several groups of people, including children, senior citizens, and some people with disabilities. Minister Mallon wishes to provide free travel for people with disabilities who currently pay half fare and to widen the range of services facilitating concessionary fares by extending the Scheme to new operators who have already indicated or expressed an interest in joining. This would significantly advance accessibility to public transport. Department for Communities Minister, Deirdre Hargey, has been urged by other parties within the Assembly to provide funding to increase the Disabled Facilities Grant due to the rising costs of construction and materials as a result of Brexit. Under the scheme applicants can receive up to £25,000 to make changes to their properties to accommodate their mobility requirements[446].

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[445] DfI (26 January 2022): Mallon signals her intention to seek approval to extend the Concessionary Fares Scheme (accessed 2 February 2022).

[446] Irish News (2021): Minister is urged to increase grant for upgrades to homes of disabled people (accessed 3 January 2022)

The Disability Strategy Expert Advisory Panel proposed the following recommendations:

- 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;
- develop clear accessibility standards in consultation with d/Deaf and disabled people and their representative organisations, considering 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 provision should be a mandatory requirement in all public spaces. These should be provided in addition to, and not instead of, standard accessible toilets;

- adopt inclusive design standards (BS8300) in its procurement policies;[447]
- 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;
- ensure all those working in transport services receive d/Deaf and disability equality training;

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[447] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, pp.75-76 (accessed 10 October 2021).

- 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 pavement.[448]

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[448] Ibid, pp. 80-81.

Article 10: The Right to Life

> *"The Government left disabled people and vulnerable people to die. They decided their lives were expendable. They continue, with the help of the Press, to push the narrative that current deaths are those with underlying conditions, to push this idea that these deaths were almost deserved".*
>
> **Disabled woman aged 25-29.**

Article 10 requires that State parties reaffirm that every human being has the right to life and that all necessary measures should be undertaken to ensure the effective enjoyment of life by persons with disabilities on equal basis with others[449].

The UNCRPD Committee were concerned that some people think that the lives of d/Deaf and disabled people are less valuable that those of non-deaf and disabled people.

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[449] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 10 (accessed 4 November 2021).

The UN Committee considered the issue of access to reproductive healthcare in the NI context and concluded that while a women's right to reproductive and sexual autonomy should be respected, provision for the termination of pregnancy at any stage on the basis of foetal impairment should not be incorporated within abortion law[450].

In its concluding observations (2017), the UNCRPD Committee has raised concerns regarding the use of substituted decision making in matters of termination or withdrawal of life-sustaining treatment and care noting that the inconsistency with respect to the right to life of persons with disabilities as equal members of society. The Committee recommends that the State party adopts a plan of action which has the overall aim of challenging perceptions that d/Deaf and disabled people do not have a good and decent life, and which encourages the recognition of people with disabilities as part of the diversity of humankind. The Committee has also recommended that the State Party ensure access to life sustaining treatment and care[451].

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[450] 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, paragraph 13 (accessed 3 November 2021).

[451] 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, paragraphs 26 and 27 (accessed 3 November 2021).

The UNCRPD Committee and the Committee on the Elimination of All forms of Discrimination against women released a joint statement on 29 August 2018. The statement welcomed progress by State Parties to enable access for women and d/Deaf and disabled women to sexual, reproductive health and rights. The Committees raised concern regarding:

- considerable gaps across all regions in the protection of these fundamental rights and freedoms and called on State parties to increase efforts with this regard;
- Increasing rollback and regression in respect for international human rights norms which threaten the sexual and reproductive health and rights of women, including d/Deaf and disabled women who continue to experience intersecting forms of discrimination.

The Committees noted that:

- gender equality rights and disability rights are mutually reinforcing concepts and that State parties should guarantee the rights of all women, including women with disabilities;
- state parties have an obligation to respect, protect and fulfil the rights of women, including women with disabilities in relation to their sexual and reproductive health and rights;

- states must ensure the enjoyment of sexual and reproductive rights of women, including women with disabilities without any form of discrimination;
- access to safe and legal abortion, as well as related services and information are essential aspects of women's reproductive health and a prerequisite for safeguarding their human rights to life, health, equality before the law and equal protection of the law, non-discrimination, information, privacy, bodily integrity, and freedom from torture and ill-treatment;
- state parties should fulfil their obligations under articles 5 and 8 of CEDAW and UNCRPD Conventions respectively by addressing the root causes of discrimination against women and persons with disabilities. This includes challenging discriminatory attitudes and fostering respect for the rights and dignity of persons with disabilities, in particular women with disabilities, as well as providing support to parents of children with disabilities in this regard. Health policies and abortion laws that perpetuate deep-rooted stereotypes and stigma undermine women's reproductive autonomy and choice, and they should be repealed because they are discriminatory;

- in order to respect gender equality and disability rights, in accordance with the CEDAW and UNCRPD Conventions, State parties should decriminalise abortion in all circumstances and legalize it in a manner that fully respects the autonomy of women, including women with disabilities. In all efforts to implement their obligations regarding sexual and reproductive health and rights, including access to safe and legal abortion, the Committees call upon State parties to take a human rights-based approach that safeguards the reproductive choice and autonomy of all women, including women with disabilities[452].

The right to life is a fundamental principle of international human rights law. Article 3 of the Universal Declaration of Human Rights (UDHR)[453] states that "everyone has the right to life, liberty, and security of person." Article 6(1) of the International Covenant on Civil and Political Rights (ICCPR)[454] provides that "every human being has the inherent right to life" which is to be "protected by law," and "no one shall be arbitrarily deprived of his life."

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[452] OHCR (2018): Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities - Joint statement by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of All Forms of Discrimination against Women

[453] UN General Assembly (1948): Universal declaration of human rights. Article 3. *UN General Assembly*, *302*(2), pp.14-25 (accessed 29 January 2022).

[454] UN General Assembly (1966): *International Covenant on Civil and Political Rights*, 16 December United Nations, Treaty Series, vol. 999, p. 171.

In June 2021, the Office for National Statistics published statistics which documented that 60% of deaths from coronavirus in the UK have been people with disabilities. d/Deaf and disabled women are more likely to die from Covid-19 than d/Deaf and disabled men[455]. NISRA published an equality group analysis of wave one deaths due to Covid-19 which showed that d/Deaf and disabled people were 40% more likely to die of Covid-19[456].

People with learning disabilities have experienced greater excess deaths from Covid-19 as well as being disproportionately affected by the lock-down procedures implemented by the UK Government and the four devolved administrations[457]. During the period 2 March to 9 June 2020, 615 Covid-related deaths of people with a learning disability were reported to the Learning from Death Reviews (LeDeR) programme at the University of Bristol[458]. This data solely relates to England.

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[455] ONS (2021): Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 15 May 2020 (accessed 27 October 2021).

[456] NISRA (2021): Covid-19 Deaths and Equality - Wave One (accessed 2 February 2021).

[457] ARC (NI) (2020): A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland, p.16 (accessed 5 November 2021).

[458] Heslop, P., Byrne V., Clakin, R., Huxor, A., Sadoo, A. and Sullivan, B. (2021): Deaths of people with intellectual disabilities: Analysis of deaths in England from COVID-19 and other causes, Journal of Applied Research in Intellectual Disabilities.

During April 2020, Disability Action[459] undertook a survey of disabled people about their experiences of the impact of the pandemic. This research found that social care services for d/Deaf and disabled people had experienced disruption[460] and a decline in physical health[461]. The survey also revealed that 72% of respondents had experienced isolation and loneliness[462], 38% reported challenges with respect to caring commitments[463] whilst 57% faced challenges in accessing food and medicine[464].

There are concerns regarding the withholding and withdrawing of medical treatment of d/Deaf and disabled people[465]. Attitudes and stereotypes of d/Deaf and disabled people have been linked to carelessness, neglect, disregard, and ignorance all of which has been linked with violations of the right to life. [466]. The withholding or restricting of resources that promote and sustain life and health may have a devastating impact on life and life chances.

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[459] Disability Action (2020): The impact of COVID-19 on disabled people in Northern Ireland (accessed 5 Nov 2021).

[460] Ibid, p.5.

[461] Ibid, p.5.

[462] Ibid, p.6.

[463] Ibid, p.6.

[464] Ibid, p.6.

[465] Ruck Keene, A.C.E. and Lee, A. (2019): Withdrawing life-sustaining treatment: a stock-take of the legal and ethical position, J Med Ethics, 45(12):794-799.

[466] Puras, D. and Gooding, P. (2019): Mental health and human rights in the 21st century. *World Psychiatry*, 2019;18 (1) (accessed 28 December 2021).

There is deep concern that the lives of d/Deaf and disabled people are being accorded less weight than non-disabled people; seemingly dispensable when decisions need to be made about critical care and access to ventilators[467].

There are concerns regarding the inappropriate use of Do Not Resuscitate (DNR) Orders[468]. Disabled people and their families, including parents of autistic children and carers of people with learning disabilities, are reporting that they have been asked to complete Do Not Resuscitate (DNR) order forms, in case they become critically ill, with no consultation[469].

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[467] Byrne, B. (ND): How the pandemic is further alienating the disabled community (accessed 28 December 2021).

[468] BBC (2021): People with learning disabilities 'living a nightmare' (accessed 28 December 2021). This article includes Amanda Paul's contribution to the Disabled People's Parliament in which Amanda recounts her own experience with respect to Do Not Resuscitate Orders.

[469] Byrne, B. (ND): How the pandemic is further alienating the disabled community (accessed 21 December 2021).

Participants in the qualitative research which informs this report told us about their experiences referring to their lives using words like disposable, expendable and a burden:

> *"Our lives are seen as disposable. That has been clear throughout Covid. Either they give us a DNR*[470] *without our consent, say that we should not live our life to the fullest or our deaths are expected and not warranted of sympathy. Accommodations miraculously became available to abled people and now the economy is opening back up, they want to remove it. Employers continue to see us as a burden, and we are unable to progress in the same way of our peers"*
>
> **Disabled woman aged 25-29.**

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[470] A Do Not Resuscitate notice.

Right to Life Case Study

Amanda Paul recounted her experience at the inaugural sitting of the Disabled Person's Parliament on 3 December 2021. Amanda was hospitalised after becoming seriously ill with septicaemia. Amanda recalled how her consultant told her that due to her weight and disability that it would be best to put a Do Not Resuscitate Order on her. Amanda described being left reeling that someone could pronounce what she felt was a death sentence on her without discussion or recourse and that she was left in tears wondering if she was going to die[471].

Participants in the qualitative research to inform this study referred to d/Deaf and disabled people being ignored, pushed out, left to die, neglected, and abused:

> *"They were totally ignored and, from personal experience of caring for an elderly disabled person, they were treated as expendable. From personal experience during the pandemic, the hospital staff stated that they would refuse to give treatment and pushed for me to sign a 'Do Not Resuscitate'.*

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[471] NI Assembly (2021): Disabled Person's Parliament, 6 December 2021 (accessed 21 December 2021).

> *When I refused, they informed me that it didn't matter, as they would not be able to be resuscitated anyway, due to the age of the person. The treatment or lack of care this person received in the hospital was basically neglect and when released from hospital they were covered in bruises".*
>
> **Disabled man carer with long-term health condition, 55-59.**

When d/Deaf and disabled people have been involved in medical training, for example, within Bristol, Leicester and Newcastle Medical Schools, students have gained an understanding of the lived experience of d/Deaf and disabled people and as a result have stronger insights into medical practice and values as they relate to the rights of d/Deaf and disabled people[472].

Northern Ireland generally reflects the right to life legislation of that of the UK. The main distinction, to date, relates to access to abortion and reproductive healthcare. Abortion in England is regulated under the criminal code via the 1861 Offences Against the Person Act but is legally available through the 1967 Abortion Act which established grounds under which abortion can be performed[473].

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[472] Shakespeare, T. and Vernon, B. (2008): Disability rights and resuscitation: Do not attempt reconciliation? In *Disabled People and the Right to Life,* pp. 115-125 London: Routledge (accessed 27 December 2021).

[473] Abortion Act 1967 (accessed 12 December 2021).

Originally, this law permitted termination up to 28 weeks of pregnancy, but this was reduced to 24 weeks in 1990. Terminations are permitted after 24 weeks in rare circumstances, including on health/life grounds and on the grounds of ‘severe disability’[474]. In 2019, abortion was decriminalised in NI[475].

Previously, Northern Ireland had been governed by the highly restrictive Offences Against the Person Act of 1861 and subsequent legal precedents that interpreted it[476]. Under this law, only a handful of pregnant people could access abortion in local hospitals each year. Some people travelled to other parts of the UK to access abortion services where they paid the same fees as non-residents[477].

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[474] Calkin, S. and Berny, E. (2021): Legal and non-legal barriers to abortion in Ireland and the United Kingdom. *Medicine Access @ Point of Care*, January 2021.

[475] Calkin, S. and Berny, E. (2021): Legal and non-legal barriers to abortion in Ireland and the United Kingdom. *Medicine Access @ Point of Care*, January 2021 (accessed 12 December 2021).

[476] Whitaker, R. and Horgan, G. (2016): *Abortion governance in the New Northern Ireland,* in: Zordo, S.D., Mishtal, J. and Anton, L. (eds.): A fragmented landscape: abortion governance and protest logics in Europe, New York: Berghahn Books, pp. 245–265.

[477] Calkin, S. and Berny, E. (2021): Legal and non-legal barriers to abortion in Ireland and the United Kingdom. *Medicine Access @ Point of Care*. January 2021 (accessed 12 December 2021).

An inquiry by the United Nations Convention on the Elimination of All Forms of Discrimination Against Women found Northern Ireland's abortion law in grave and systematic violation of the Convention in 2018[478]. Subsequently, the majority of judges in a 2018 Supreme Court Case, brought forward by the Northern Ireland Human Rights Commission (NIHRC), found the abortion law to be incompatible with human rights law[479].

Stella Creasy MP tabled an amendment that would decriminalise abortion in Northern Ireland, should there not be a sitting Northern Ireland Assembly by 21 October 2019. On 22 October, with Stormont still not functioning, this law took effect and repealed sections 58 and 59 of the 1861 law[480]. In repealing these sections and imposing a moratorium on all criminal proceedings relating to an offence under those sections, the new law decriminalised abortion in Northern Ireland.

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[478] UN Committee on the Elimination of Discrimination against Women (2018): Report of the inquiry concerning the United Kingdom of Great Britain and Northern Ireland under article 8 of the optional protocol to the convention on the elimination of all forms of discrimination against women, p.18 (accessed 12 December 2021).

[479] UK Supreme Court. Judgment 2018 UKSC 27 (accessed 12 December 2021).

[480] Calkin, S. and Berny, E. (2021): Legal and non-legal barriers to abortion in Ireland and the United Kingdom. *Medicine Access @ Point of Care*, January 2021 (accessed 12 December 2021).

Under regulations in effect from 31 March 2020, abortion is now legal without conditionality up to 12 weeks gestation; and up to 24 weeks gestation where the pregnancy would risk the physical or mental health of the pregnant person greater than the risk of terminating the pregnancy[481]. In cases of foetal abnormality and where there is risk to the person's life, there is access to abortion with no gestational time limit.

The Abortion Regulations (NI) 2020 came into effect on 31st March 2020[482]. Contrary to the Committee's recommendations, the regulations permit access to abortion services in cases of severe foetal impairment (SFI) and fatal foetal abnormalities (FFA) with no gestational time limit. This is where there is a substantial risk that the condition of the foetus is such that the death of the foetus is likely before, during or shortly after birth; or if the child were born, it would suffer from such physical or mental impairment as to be seriously disabled.[483]

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[481] HM Government (2019): A new legal framework for abortion services in Northern Ireland: government consultation (accessed 12 December 2021).

[482] The Abortion (Northern Ireland) Regulations 2020 (accessed 26 October 2021).

[483] House of Commons Library (2021): Abortion in Northern Ireland: Recent Changes to the Legal Framework, paragraph (iii) p.15 (accessed 26 October 2021).

The UN Human Rights Committee has adopted the view that laws which explicitly allow for abortion on the grounds of disability violate Article 6 of the International Covenant on Civil and Political Rights on the right to life.[484] The March 2020 law did, however, re-introduce criminal penalties for ‘unlawful terminations’[485].

Despite its 2019 abortion decriminalisation, and over a year since the new regulations took effect, the Northern Ireland Health Minister is yet to commission abortion services. Until services are commissioned, the task of providing early medical abortion services has fallen to Northern Ireland’s five local Health and Social Care Trusts. Most of the Trusts are only providing abortion up to 10 weeks gestation, rather than 12 weeks[486].

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[484] UN Human Rights Committee (HRC): General comment no. 36, Article 6 (Right to Life), 3 September 2019, CCPR/C/GC/35, paragraph 6.1, p.13 (accessed 5 November 2021).

[485] The abortion (Northern Ireland) regulations 2020, s11 (accessed 12 December 2021).

[486] Topping, A. (2021): UK ministers face legal action over lack of abortion services in Northern Ireland, The Guardian, 10 January 2021 (accessed 12 December 2021).

The Northern Ireland Human Rights Commission, with others, took a legal case against the Secretary of State for Northern Ireland and the Department of Health for Northern Ireland in 2021 arguing that the lack of equal access to abortion services was a breach of the European Convention on Human Rights[487].

Judge Colton in his verdict noted that the Department of Health would be further constrained by the fact that the Executive would have to agree commissioning proposals when complete[488]. The ongoing challenges for women, girls, and pregnant people in NI to access abortion services impacts especially on those who are already marginalised, including women with disabilities.[489]

d/Deaf and disabled people and in particular persons with intellectual and psychosocial disabilities are at high risk of human rights abuse, including violations of the right to life[490].

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[487] NIHRC (2021): Human Rights Commission Legal Action on Lack of Abortion Services in NI Begins, 25 May 2021, (accessed 26 October 2021).

[488] Neutral Citation No: [2021], NIQB 91, paragraph 68.

[489] Abortion Support Network (2018): Written submission from Abortion Support Network (ANI0369) (accessed 26 October 2021).

[490] Human rights. Yes! (2012): Action and Advocacy on the Rights of Persons with Disabilities, 2nd Ed., Human Rights Education Series: Topic Book 6a. Minnesota: University of Minnesota.

When placed in institutions, d/Deaf and disabled people may be subject to forced treatment, violence, unhygienic conditions, use of physical constraints, lack of food, water, and appropriate health care, all of which can contravene the right to life[491].

All too often there is no effective investigation into the circumstances of the person's death. In 2014, the European Court of Human Rights found a violation of the right to life under the European Convention on Human Rights in the case of a young man with intellectual disability who was abandoned in an institution at birth and died in a psychiatric hospital at the age of 18[492].

The suicide rate is high amongst d/Deaf and disabled people, especially those with intellectual and psychosocial disabilities[493]. Mental Health services are underfunded[494]. There is poor provision of mental health services particularly for people who are experiencing mental health crises and emotional distress[495].

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[491] BBC (2020): Muckamore Abbey Hospital: Timeline of abuse allegations (accessed 13 December 2021).

[492] European Court of Human Rights (2014): Case of centre for legal resources on behalf of Valentin Campeanu v Romania, Application no. 47848/08 (accessed 13 December 2021).

[493] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.97 (accessed 10 October 2021).

[494] UK Parliament (2019): Health Funding in Northern Ireland, paragraphs 115-125 (accessed 10 October 2021).

[495] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations.p.97 (accessed 10 October 2021).

The Protect Life 2 Strategy was published in September 2019[496]. Although the Strategy recognises that physical and sensory disability is a suicide risk factor[497], there is no specific commentary as to why or recommendation as to how the enhanced risk can be addressed. There is an opportunity for the new Disability Strategy to prioritise addressing suicide, mental health crisis and mental health distress.

Professor Siobhan O'Neill was appointed Mental Health Champion by the Department of Health in September 2021, having occupied the role in an interim basis from the June 2020[498]. The Champion is tasked with ensuring that the voices of people who struggle with poor mental health are heard and influence policy and strategy.

In line with commitments made as part of the 'New Decade, New Approach' agreement[499], Health Minister Robin Swann launched the publication of the new Mental Health Strategy 2021-2031 on 29 June 2021[500]. The Strategy includes a commitment to provide enhanced and accessible mental health services for those who need specialist mental health services, including children and young people with disabilities.

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[496] DoH (2019): Suicide Prevention Strategy - 'Protect Life 2' published today. (accessed 2 November 2021).

[497] DoH (2019): Protect Life 2 - Suicide Prevention Strategy, p.28 (accessed 2 November 2021).

[498] DoH (2021): Mental Health Champion appointed, 8 September 2021, (accessed 2 Nov 2021).

[499] UK Government (2020): New Decade New Approach, p.7 (accessed 1 November 2021).

[500] DoH (2021): Mental Health Strategy 2021-2031 (accessed 13 December 2021).

The strategy states that the services must be able to cater for those with disabilities, including physical and sensory disabilities, ASD and intellectual disabilities and must include help and support for parents and families[501].

The strategy places an emphasis upon early intervention[502] and includes a commitment to develop an action plan which will include targeted approaches to groups more likely to be adversely affected by mental ill health including people with a physical or sensory disability and persons with an intellectual disability[503].

The Mental Health Strategy cross references the four proposed social inclusion strategies noting that the strategies are likely to include cross-departmental interventions which will contribute to mental health and wellbeing[504]. It is therefore important that the Disability Strategy dovetails other strategies[505].

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[501] Ibid, Action 7, VIII.

[502] Ibid, paragraph 45, p.26.

[503] Ibid, paragraph 54, p.31.

[504] Ibid, paragraph 56, p.32.

[505] Ibid, paragraph 20. p16.

The authors of this report recommend:

- the development and adequate resourcing of appropriate services that promote independent living, meet needs, and enable a life of choices, opportunities, and participation;
- the resourcing and reform of mental health services to better address the needs of d/Deaf and disabled people;
- the development and resourcing of a Suicide Prevention Strategy which is built on the premise that every life matters and which ensures that those at risk of suicide have access to skilled and well-co-ordinated support ;
- the removal of barriers to mental health provision by reducing waiting times by investing in enhanced provision;
- the implementation of a human rights framework to the delivery of healthcare which enshrines the right to equality of access to treatment;
- the recognition of the right to personal autonomy and an end to substituted decision making;
- the end to the inappropriate use of DNR and improved communication of the realities of resuscitation to patients;

- better training of staff within the Health Service to include disability equality and disability rights perspectives. This training should be developed with d/Deaf and disabled people;
- effective investigations of deaths and alleged ill-treatment to prevent mistreatment and deaths in institutions by revealing circumstances of deaths and effectively addressing malpractice and mistreatment including neglect.

Article 11 Situations of Risk and Humanitarian Emergencies

> *"People with disabilities are being failed by our government during the pandemic; no access to day centres. Not enough support for carers -they are being completely ignored by our Health Minister at every wheel and turn. More transparent information to every sector, especially to schools, health professionals and carers needs updated."*
>
> **Disabled woman carer with long-term health condition, 40-44.**

Article 11[506] requires that State Parties shall take all necessary measures in accordance with their obligations under International Humanitarian Law and International Human Rights Law 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[507].

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[506] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 11 (accessed 4 November 2021).

[507] Ibid.

In its (2017) concluding observations, the UNCRPD Committee were concerned about the impact of situations of emergencies such as fires and floods on persons with disabilities. The Committee also commented on the absence of comprehensive policies related to disaster reduction that include persons with disabilities in the planning, implementation, and monitoring processes of disaster reduction. The Committee recommended that the State Party:

- adopt a comprehensive disaster reduction plan and strategies which provide for accessibility and inclusion of people with disabilities in all situations of risk, in line with the Sendai Framework for Disaster Risk Reduction[508], in close consultation with DPOs;
- mainstream disability into all humanitarian challenges and that DPOs are involved in setting priorities of aid distribution in the context of risk and humanitarian emergencies, paying attention to the Charter on Inclusion of Persons with Disabilities in Humanitarian Action;
- develop information and warning systems in humanitarian emergencies that are accessible for all persons with disabilities;

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[508] UNISDR (United Nations International Strategy for Disaster Reduction). (2015). Sendai framework for disaster risk reduction 2015–2030 (accessed 23 February 2022).

- ensure that DPOs participate in resilience teams at the local level and have an active role in advising on and formulating policies and guidelines regarding disaster preparedness.[509]

The ongoing Covid-19 crisis has brought the significance of Article 11 to the fore. Concerns have been raised regarding the extent to which the views of disabled peoples, carers and service users were addressed during Covid-19.

> *"Disabled people were not included in Covid response planning, otherwise mask exemptions would not be exploited by anti-maskers and GPs would not be getting away with phone call appointments. How can a doctor examine me via a phone? We were not even a thought in the Government's mind during Covid planning. 60% of all covid deaths in UK have been disabled people. If that's not a sign of our supposed insignificance, then what is?"*
>
> **A disabled man carer long-term health condition, 16-24.**

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[509] 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, paragraphs 29 and 30 (accessed 5 November 2021).

The Covid-19 crisis emerged in early 2020 at an unprecedented rate. There is a consensus that the pandemic has exacerbated existing inequalities, with increased difficulties food shopping and getting medical essentials and reduction in vital care support[510]. Participants in the qualitative research which informs this report were very clear on the challenges facing disabled people in the context of Covid-19 and the continued uncertainty with respect to Brexit:

> *"I think measures to protect people with disabilities are likely to get worse - particularly in relation to access to health and education with the COVID-19 pandemic. Brexit is also likely to have a negative impact on people with disabilities particularly in relation to access to health and freedom of movement - with lack of agreement on important issues such as access to medicines and assistance dogs - in these arguments the rights of disabled people are not being considered. I am on biologics that are sent directly from GB, and I worry that lack of agreement may mean I will no longer be able to readily access my treatment"*
>
> **Disabled woman carer with long-term health condition, 45-49.**

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[510] ECNI (2020): People with disabilities must not be left behind by response to COVID-19 (accessed 28 December 2021).

Reports from the Joint Committee on Human Rights[511] and the Women and Equalities Committee[512] have assessed the impact of coronavirus and legal changes during the pandemic on the rights of d/Deaf and disabled people. The commentary within this report under Article 10, the Right to Life, outlines the negative implications of Covid-19 on the Right to Life of d/Deaf and disabled people. d/Deaf and disabled people are more likely to die as a result of Covid-19, have been subject to inappropriate Do Not Resuscitate Orders and have experienced challenges in accessing health care[513].

Covid-19 Case Study

Joe Kenny is blind and described how little thought was given to his needs when it came to accessing safety measures during the pandemic at the Disabled Person's Parliament on 3 December 2021.

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[511] Joint Committee of Human Rights (2020): The Government's response to COVID-19: human rights implications (accessed 26 of October 2021).

[512] Women and Equalities Committee (2020): Unequal impact? Coronavirus, disability, and access to services: interim Report on temporary provisions in the Coronavirus Act (accessed 26 of October 2021).

[513] ONS (2021): Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 15 May 2020 (accessed 27 October 2021).

Joe described that when he went shopping at the beginning of the pandemic he walked into the door at a supermarket and was told that he had to go and stand at the back of queue that he could not see how to join. This situation emerged because supermarkets solely employed visual information to explain the queuing system.

Joe referred to being locked out of society. Joe also described barriers in accessing a PCR test due to the lack of provision for blind people. The current provision of healthcare does not address his needs or that of his family. Remote GP care is not fully accessible to blind people. Joe struggled to take photo of his son's eye to achieve a diagnosis remotely from his GP[514].

The degree to which the emergency response of the Executive to the Covid-19 crisis included people with disabilities and addressed their needs has been called into question by d/Deaf and disabled people and by the Equality Commission for Northern Ireland[515].

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[514] NI Assembly (2021): Disabled Person's Parliament, 6 December 2021. (accessed 21 December 2021).

[515] ECNI (2020): People with disabilities must not be left behind by response to COVID-19 (accessed 5 November 2021).

Initial guidance from government agencies was not attuned to the needs of persons with learning disabilities and their living situations; particularly for those in supported living arrangements rather than residential homes. The guidance from different agencies was contradictory and had not been developed through consultation with organisations and personnel with the necessary expertise. Revised guidance has been made available, but a lack of consultation remains an issue beyond Covid-19[516].

The recent engagement between the Executive and d/Deaf and disabled people on proposed changes to mask exemption regulations is an example of best practice. Working closely together d/Deaf and disabled people and the Executive identified solutions. A close working relationship between the Executive and d/Deaf and disabled people has emerged from this. This is a welcome development[517].

Participants in the qualitative research which informs this report told us that they felt let down and neglected by the Government and statutory services throughout the pandemic:

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[516] ARC (NI) (2020): A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland, p.8 (accessed 5 November 2021).

[517] Disability Action (2022): Face Coverings: Proof of exemption is not required (accessed 2 Feb 2022).

> *"We have been totally neglected throughout and are still being ignored by our governments and statutory bodies. From accessing healthcare extra financial support and general support. Disabled people have and have always been neglected and we're put to the bottom of the pile, and it leaves us feeling more vulnerable and isolated than ever".*
>
> **Disabled woman carer with long-term health condition, 40-44.**

Participants in the qualitative research which informs this report have told us that they feel like second class citizens who feel excluded and powerless in the context of decisions that are made about their care and lives:

> *"We are less than second class citizens and it appears are feelings are not taken into consideration when planning our care. We have no voice"*
>
> **A disabled person who is also a carer.**

Families and carers were cut-off from face-to-face support, further compounded by the abrupt closure of statutory services, such as day centres, respite care and professional services[518]. The withdrawal of these services left many family carers unsupported. The subsequent slow and reduced opening of these services has prolonged the carers' stress and anxiety[519].

The immediate closure of face-to-face services in late March 2020 created unprecedented pressures on the non-statutory sector. New forms of remote support, based around various information technologies, evolved jointly with service-users. ARC (NI) has recommended that the most popular and successful ones should be incorporated into future provision[520].

The cessation of services, particularly those which were provided to people with intellectual or psychosocial disabilities was particularly problematic, with parents, carers and service users left in anxious and unstable situations which caused significant disruption[521].

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[518] Disability Action (2020): The impact of COVID-19 on disabled people in Northern Ireland (accessed 5 Nov 2021).

[519] ARC (NI) (2020): A review of the impact of COVID-19 on learning disability services provided mainly by the voluntary sector in Northern Ireland, p.10. (accessed 5 November 2021).

[520] Ibid, p.9.

[521] Ibid, p.8.

The cessation of statutory services also placed significant pressure on the voluntary sector to intervene[522]. The report by ARC (NI) recognised that it is essential that contingency plans are put in place for further Covid-19 surges or similar emergencies. The safety of d/Deaf and disabled persons should be a core consideration and their emotional and social well-being prioritised in the planning of services. ARC (NI) proposed that lessons learned from the Covid-19 crisis, particularly in the context of the role played by the Voluntary Sector should be considered within the transformation of adult social care[523].

The voluntary and community sector in Northern Ireland has made a major contribution to transforming the social care provided to persons with learning disabilities, notably towards a more person-centred, community-based approach. Their experience and expertise qualify them to be full partners with statutory services in the process of recovery and renewal of services post-Covid-19 in line with the aspirations for the transformation of adult social care[524]. That partnership should also extend to d/Deaf and disabled people themselves. Assurances also need to be given regarding continuity of contracts to ensure the financial stability of the services provided by the non-statutory sector.

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[522] Ibid, p.7.
[523] Ibid, p.8.
[524] Ibid, p.10.

Concerns have been raised regarding the roll-out of the vaccine programme and whether the programme has been inclusive to d/Deaf and disabled people[525]. Vaccine information materials were developed in accessible formats to people, but the vaccine letters were sent out to people in inaccessible formats[526]. There was little consultation with d/Deaf and disabled people regarding the vaccine rollout strategy[527]. Participants in the research to inform this report raised concerns that d/Deaf and disabled people did not have the same access to information as non-disabled people and experienced challenges in accessing vaccination centres:

> *"We need more information about vaccines - disabled people were not given same information as able bodied people - and going for vaccinations has been difficult for some regarding access issues with venues".*
>
> **Disabled woman aged 60-64.**

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[525] Voluntary Organisations Disabilities Group (ND): VODG calls on government to ensure disabled people are not left behind in rollout of COVID-19 vaccine

[526] Ibid, p.7.

[527] Leonard Cheshire (ND): Delivering a disability-inclusive COVID-19 vaccine programme: Guidance note, Section 1, p.2 (accessed 24 December 2021).

Leonard Cheshire has recommended:

- multi-stakeholder consultations on the development of a disability inclusive vaccination strategy which should include DPOs, disabled people, civic society and government representatives[528];
- vaccine roll out strategies should give priority to d/Deaf and disabled people and their support networks[529];
- vaccine centres must be accessible for people with a range of disabilities. Disability accessibility audits should be undertaken to ensure that all vaccination centres have ramps or step free access;
- outreach should be undertaken to enable people with disabilities and particularly with people with sensory or intellectual disabilities to access vaccination. This should include home visits for people unable to reach vaccine centres and transportation services[530];
- properly resource DPOs to become partners in roll out information campaigns that reach the most marginalised populations and ensure that messages are clear, inclusive, and accessible[531];
- ensure that booking technology is fully accessible and consult with DPOs to ensure that this is the case[532].

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[528] Ibid.

[529] Ibid, p.5.

[530] Ibid, p.6.

[531] Ibid, p.7.

[532] Ibid.

The 2020 report, ‘An Affront to Dignity, Inclusion and Equality’[533] argues that there has been a failure to provide reasonable adjustments to people with disabilities during the ongoing Covid-19 crisis leading to widening inequality. The report concluded that the Government failed to take appropriate steps to include d/Deaf and disabled people in planning across all policy areas in response to the Covid-19 crisis[534].

The Executive published a Covid-19 recovery plan in August 2021[535], following a limited 1-week consultation with only a small number of disability and other organisations including the Equality Commission for Northern Ireland and one DPO[536]. Disability Action consider that one of the significant failings of the plan is that it focuses mainly on aspirational statements intended to describe the general direction of travel to achieve economic, health and societal recovery.

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[533] Tidball, M., Lawson A., Herring J., Sloan, B., Holloway, D. and Ryan, S. (2020):): An Affront to Dignity, Inclusion and Equality: Coronavirus and the Impact of Law, Policy, Practice and Access to Services on People with Disabilities in the United Kingdom, (Oxford University Disability Law & Policy Project and the Bonavero Institute of Human Rights) (accessed 26 October 2021).

[534] Tidball, M., Lawson A., Herring J., Sloan, B., Holloway, D. and Ryan, S. (2020): An Affront to Dignity, Inclusion and Equality: Coronavirus and the impact of law, policy and practice on people with disabilities in the United Kingdom, Executive Summary. p.3 (accessed 27 October 2021).

[535] TEO (2021): Building Forward: Consolidated Covid-19 Recovery Plan (accessed 5 Nov 2021).

[536] The research team preparing this report engaged with a number of DPOs and Northern Ireland-wide disability organisations and found that only 1 DPO had been consulted and that their views on the Covid Recovery Plan were not reflected in the final publication of The Executive Office (2021): Covid Recovery Plan (accessed 3 January 2022).

The Plan contains no detailed consideration of equality issues or human rights perspectives. The Plan draws attention to a wide range of existing strategies, policies and programmes published prior to the Covid-19 pandemic and takes a medical model approach (addressing vulnerability) rather than a human rights-based approach. Disability[537] is only referenced once[538] whilst the Plan lacks actions or quantifiable outcomes to address issues faced by d/Deaf and disabled people because of the pandemic. The associated Action Plan contains no actions or quantifiable outcomes to address issues faced by disabled people because of the pandemic. The Action Plan contains equally aspirational measures and talks about addressing vulnerability and does not adopt a human rights-based model approach. The Plan draws attention to a wide range of existing strategies, policies and programmes published prior to Covid-19 pandemic.

The authors of this report propose the following recommendations:

- the implementation of a human rights framework to the delivery of healthcare which enshrines the right to equality of access to treatment;
- the recognition of the right to personal autonomy and an end to substituted decision making;

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[537] Ibid, p.10.

[538] In relation to a focus on needs-based skills enhancement of the 14–19-year-olds.

- the end to the inappropriate use of DNR and improved communication of the realities of resuscitation to patients;
- better training of staff within the Health Service to include disability equality and disability rights perspectives. This training should be developed with d/Deaf and disabled people;
- the Executive takes account of Articles 10 (Right to Life) and 25 (Health) of the UN Convention of the Rights of Persons with Disabilities (UNCRPD) in its approach to dealing with COVID-19, by providing d/Deaf and disabled people, older people, and carers with reassurance they will have equal access to hospital treatment, health, and social care services;
- in line with Article 4(3) of the UNCRPD (General Obligations), the Executive establishes, without delay, a mechanism to consult with and actively engage with d/Deaf and disabled people (including disabled children) in planning and delivering the next phase of its response to COVID-19. It is essential that the needs of d/Deaf and disabled people are addressed within every plan and change in regulations;
- involves d/Deaf and Disabled people in economic planning as the disability employment gap is wider in NI when compared with other regions of the UK;

- prioritise and resource the Disability Strategy and ensure it provides a clear plan to mitigate existing inequalities magnified by the impact of the pandemic.

Article 12: Equal recognition before the law

Article 12 reaffirms that persons with disabilities have the right to equal recognition as persons before the law and requires that d/Deaf and disabled people enjoy legal capacity on an equal basis with others, and that effective measures are in place to safeguard and protect against abuse. Article 12 seeks that State parties take appropriate measures to provide persons with disabilities with the support which they require to exercise their legal capacity[539].

The UNCRPD Committee raised concerns, in its (2017) concluding observations, about legislation within NI that restricts the capacity of persons with disabilities based on perceived or actual disability; the prevalence of substituted decision making in practice in legislation and practice; the lack of recognition of the right to supported decision making that respects autonomy.

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[539] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 12 (accessed 4 November 2021).

The Committee recommends that the State Party, in close consultation with DPOs, including those representing persons from black and minority ethnic groups and in line with General Comment No. 1 (2014) on equal recognition before the law, abolish all forms of substituted decision-making by reviewing and adopting new legislation in accordance with the Convention to initiate new policies in both mental capacity and mental health laws[540].

There are two key pieces of legislation that are relevant to examining mental health and capacity laws in Northern Ireland: The Mental Health (Northern Ireland) Order 1986 (MHO) [541] and the Mental Capacity (Northern Ireland) Act, 2016 (MCANI)[542]. The Mental Capacity Act (2016) provides for determinations of unfitness to plead and the defence of insanity which represent disability discrimination in context of the UNCRPD.

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[540] 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, paragraphs 30 and 31 (accessed 3 November 2021).

[541] The Mental Health (Northern Ireland) Order 1986 (accessed 3 November 2021).

[542] Mental Capacity Act (NI) 2016 (accessed 3 November 2021).

The MHO[543] provides for involuntary treatment of 'mental disorder', which is defined as 'mental illness, mental handicap and any other disorder or disability of mind' (MHO, Article 3(1)). This is based on diagnosis and risk; presence of mental illness or severe mental impairment; and failure to detain, leading to substantial risk of serious physical harm to self or others (MHO, Articles 3 and 4)[544].

d/Deaf and disabled people living in Northern Ireland face significant challenges in exercising legal capacity[545]. The Mental Health Capacity Act (2016) was considered to provide a framework to enable people to make decisions for themselves but falls short in doing so. Children under the age of 16 have not been included within the Mental Capacity Act in NI[546]. The Act has not been fully implemented because of delays arising from the collapse of the political institutions in NI from December 2016- January 2020.

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[543] The Mental Health (Northern Ireland) Order 1986

[544] The MHO is accompanied by a short Code of Practice, and what is known as the GAIN Guidelines, which set out detailed information about the provision of mental health care in line with the MHO.

[545] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.30 (accessed 10 October 2021).

[546] Children's Law Centre (No Date): Written Evidence to the Ad Hoc Joint Committee on the Mental Capacity Bill, paragraph 2.2. p.2 (accessed 4 Nov 2021).

The first phase of the Act came into operation in two stages - research provisions commenced on 1 October 2019, and provisions in relation to deprivation of liberty, offences and money and valuables in residential care and nursing homes commenced on 2 December 2019. The 1986 Order continues to run parallel to the Act. The provision of support to exercise capacity within Northern Ireland is limited. There are aspects of good practice among some Trusts, but these options are not equally accessible or available across the region[547].

d/Deaf and disabled people have told Disability Action that other measures, additional to the legislative aspects concerning exercise of capacity, need to be taken including training for d/Deaf and disabled people, carers, advocates and health and social care professionals to ensure equal recognition before the law for deaf and deaf and disabled people[548].

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[547] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.32 (accessed 10 October 2021).

[548] Disability Action Case Load 2020; Nothing About Us Without Us! The Human Rights of Disabled People, 24 November 2021.

The Disability Expert Advisory Panel has proposed the following recommendations:

- repeal the 2016 Act and enact 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 d/Deaf and 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[549].

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[549] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.33 (accessed 10 October 2021).

Article 13 Access to Justice

> *"I've received verbal abuse for being a young disabled person - either when using mobility aids and people mock or try and take them, or when I haven't had mobility aids and I've been accused of faking, and I have been shouted at when using my blue badge for parking".*
>
> **Disabled woman and carer aged 25-29.**

Article 13 requires State parties to ensure that d/Deaf and disabled people have effective access to justice on an equal basis with others. This includes procedural and age-appropriate accommodations to participate in legal proceedings. The Article also requires that provision of training for all relevant personnel involved in the administration of justice[550].

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[550] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 13 (accessed 4 November 2021).

Article 13 employs a broad understanding of the legal process. It specifically mentions all legal proceedings which include criminal as well as civil proceedings and quasi-judicial tribunals. As with other Articles within the Convention, Article 13 has a close relationship to other rights set out within the Convention, including Articles 5 Equality and non-discrimination[551], Article 6 Women with disabilities[552], Article 7 Children with disabilities[553], Article 9 Accessibility[554], Article 21 Freedom of expression and access to information[555], Article 24 Education[556], Article

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[551] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 5 Equality and non-discrimination (accessed 4 November 2021).

[552] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 6 Women with disabilities (accessed 4 November 2021).

[553] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 7 Children with disabilities (accessed 4 November 2021).

[554] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 9 Accessibility (accessed 4 November 2021).

[555] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 21 Freedom of expression and opinion, and access to information.

[556] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 21 Education (accessed 4 November 2021).

27 Work and Employment[557], and Article 28 Adequate standard of living and social protection[558].

Hence the concept and understanding of access to justice has a very broad application.

The UNCRPD Committee raised concerns, in its (2017) concluding observations, regarding:

- the low levels of awareness amongst justice and law enforcement officials regarding the rights of d/Deaf and disabled people;
- the lack of access to appropriate support in exercising legal capacity and access to justice by people with psychosocial and/ or intellectual disabilities;
- the barriers faced by d/Deaf and disabled people in accessing civil legal aid as a consequence of restrictions in legal aid and access to tribunals;
- the exclusions of people with hearing impairments from participation in jury proceedings; and
- that personal assistants/interpreters were not deemed procedural accommodations.

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[557] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 27 Work and Employment (accessed 4 November 2021).

[558] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 28 Adequate Standard of Living and Social Protection.

The Committee recommends that the State Party, in collaboration with DPOs:

- develops and implements capacity-building programmes among the judiciary and law enforcement personnel regarding the rights of d/Deaf and disabled people;
- design and implement a decision making regime with respect to the will and preferences of d/Deaf and disabled people within court proceedings;
- provide free legal aid for d/Deaf and disabled people in all areas of law and remove financial barriers in accessing court or tribunals;
- ensure that all d/Deaf and disabled people enjoy the right to justice with adequate procedural accommodation;
- enable deaf people to participate in jury proceedings through the use of sign language interpreters; and
- take measures to ensure d/Deaf and disabled people are empowered to work at all levels within the justice system with the provision of all necessary support[559].

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[559] 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. paragraphs 32 and 33 (accessed 3 November 2021).

Research on disability rights within the justice system has tended to centre upon the trial process, and in particular, the future of the insanity defence and fitness to plea[560]. Attention was focused upon this issue following a comment made by the UN Office of the High Commissioner of Human Rights concerning the possible introduction of disability-neutral defences to comply with Article 12 which outlines the right of d/Deaf and disabled people to enjoy the right to legal capacity on an equal basis with others[561].

Access to justice is one of the fundamental guarantees of international human rights law and is integral to the principle of equality before the law[562]. The right to justice includes effective access to procedures, information and locations used in the administration of justice[563]. The Disability Strategy Expert Advisory Panel has identified significant barriers to d/Deaf and disabled people's access to justice[564].

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[560] McNamara, D. (2018): Insanity Defence, Indefinite Detention, and the UN Convention on the Rights of Persons with Disabilities, Dublin University Law Journal, 41(1), 143.

[561] United Nations High Commissioner for Human Rights (26 January 2009): Thematic Study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, UN Doc A/HRC/10/48.

[562] United Nations (1948): Universal Declaration of Human Rights, 194. art 7.

[563] Lord, J. E., Guernsey, K. N., Balfe, J. M., Karr, V. L., deFranco, A. S. and Flowers, N. (2009): Human Rights. YES! Action and Advocacy on the Rights of Persons with Disabilities (One Billion Strong and the University of Minnesota Human Rights Center).

[564] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.98 (accessed 10 October 2021).

These include physical barriers such as the accessibility of police stations, attitudinal barriers - for example, the absence of training with respect to disability for those involved in the criminal justice system - and procedural barriers which include accessible information and legal aid[565]. Participants in the qualitative research which informs this report described how d/Deaf and disabled people are more vulnerable to crime and face challenges in accessing the justice system:

> *"The issue is mostly two-fold, the first being that the disabled themselves (especially those with learning difficulties) can be easily manipulated and/or taken advantage of in illegal ways, or they may not be aware of how to get support. The other side of the issue is that the legal support they can receive may not be adequate, for example their legal council may not know enough about disabilities to present accurate legal advice".*
>
> **Disabled man aged 16-24.**

Barriers exist with respect to reporting crime, and accessing legal advice and legal representation[566].

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[565] Edwards, C., Harold, G., and Kilcommins, S. (2012): Access to Justice for Deaf and deaf and disabled people as Victims of Crime in Ireland, University College Cork.

[566] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.98 (accessed 10 October 2021).

> *"Legal aid not as readily available. Getting legal advice is expensive and this is off-putting. Most people just give up".*
>
> **Disabled woman carer with long-term health condition, 60-64.**

There are barriers with respect to giving evidence in court and assistance to participate in legal processes[567]. There is a lack of knowledge within the legal system of how to book sign language interpreters, and the role of interpreters (who have a multi-faceted communication role between legal professionals and deaf people)[568].

Evidence suggests that professionals within the legal systems tend to have a lack of interaction with the deaf community. For example, a deaf person in Northern Ireland rang the police in England, even though there was a police station close to them in Northern Ireland because the legal system was considered inaccessible to deaf people[569].

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[567] Ibid.

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

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

There is evidence to suggest that d/Deaf and disabled young people have difficulty accessing the legal system and that persons appointed to represent d/Deaf and disabled children in court are not always aware of the issues affecting d/Deaf and disabled children or adults relating to their access to the justice system[570].

Addressing these barriers will require a more collaborative approach between police officers, probationary services, the court service, mental health services, d/Deaf and disabled people and DPOs to ensure the realisation of the rights contained within the UNCRPD and to address the systemic barriers which d/Deaf and disabled people face when engaging with the criminal justice system[571].

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[570] Northwest Forum of People with Disabilities Casework (2018). A deaf child with communication issues was not engaged with by the social worker appointed to represent the child's interests in the court system on the grounds that that it would be too difficult and expensive to provide a sign language interpreter to ascertain the child's views. The Forum made representation on behalf of the child that with some effort and minimal resources the child's views could be ascertained as to the wishes of the child and the allegations of physical abuse.

[571] Grant, E. and Neuhaus, R. (2012): Liberty and Justice for all: The Convention on the Rights of Persons with Disabilities, ILSA Journal of International and Comparative Law, 19, 347.

Disability hate crime has increased by 16% in 2020/2021, according to the Police Service Northern Ireland (PSNI)[572]. Participants in the qualitative research informing this report have told us of their experiences of hate crime, of being victimised, abused, and hurt:

> *"I have been hurt, I have been hurled with abuse and derogatory hate from sectors within the community. I have been physically attacked and abused and all because of being different".*
>
> **Disabled woman carer with long-term health condition, 40-44.**

There is no specific hate crime legislation in Northern Ireland for d/Deaf and disabled people or for people with other characteristics protected under equality law. The Criminal Justice (No.2) (NI) Order 2004[573] enables a sentence to be increased where it is proven that the basic offence for which a person has been convicted was motivated by hate crime against one of the currently protected characteristics (race, religion, sexual orientation, or disability).

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[572] PSNI (2021): Incidents and Crimes with a Hate Motivation Recorded by the PSNI: Update 30th June 2021 (accessed 4 November 2021).

[573] The Criminal Justice (No. 2) (Northern Ireland) Order 2004 (accessed 25 March 2022).

This legislation has been criticised because the hate element of the crime is only considered at the sentencing stage and can sometimes be overlooked. The person is only charged with the crime of assault rather than the hate element that motivated it. The charge is assault, and the hate element of the crime is not recorded in the charges.

Judge Desmond Marrinan was appointed by the Department of Justice to carry out an independent review of hate crime legislation in 2019[574]. The review was established to address the following issues:

- a workable and agreed definition of a hate crime;
- whether the current enhanced sentence approach is appropriate for Northern Ireland;
- whether new categories of hate crime should be created for characteristics such as gender and any other characteristics (which are not currently covered);
- the implementation and operation of the current legislative framework for incitement offences, in particular Part III of the Public Order (Northern Ireland) Order 1987 and make recommendations for improvements;

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[574] DoJ (2019): Review of Hate Crime Legislation launched (accessed 11 December 2021).

- how any identified gaps, anomalies and inconsistencies can be addressed in any new legislative framework ensuring this interacts effectively with other legislation guaranteeing human rights and equality;
- whether there is potential for alternative or mutually supportive restorative approaches for dealing with hate motivated offending[575].

The review considered key questions including increased sentencing for hate crime[576] and whether false befriending of an intellectually disabled person should be considered hostile[577]. The review:

- noted increases in online disability hate crime[578];
- noted the proven difficulties regarding disability hate crime including the persistent debasing and degrading violence which can be conceptualised as taking an advantage of vulnerability, recognising significant challenges in considering whether these crimes are hate crimes[579];

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[575] Ibid.

[576] DoJ (2020): Hate crime legislation independent review, Recommendation 3, p.10.

[577] Ibid, paragraph 6.53, p. 147.

[578] Ibid, paragraph 13.11, p.474.

[579] Ibid, paragraph 6.77, pp.154-155.

- considered the relationship between acquisitive crime and sexual exploitation and the perceptions that disability may result in the victim being less likely to resist than non-disabled victims[580];
- questioned whether discriminatory selection could be defined as discriminatory or as a form of hatred[581];
- raised concerns regarding broadening of the definition of hate crime in the context that not all unacceptable behaviour may be bigotry[582];
- recognised that the current legislation under the DDA 1995 is currently failing disabled victims[583].

Judge Marrinan made 34 recommendations[584]. The Department has indicated that Recommendation 6: A New Hate Crime model is to be considered further. The model proposed a third "by reason of" threshold to supplement the current thresholds of demonstration of hostility and motivation. The third threshold was proposed to protect people considered to be vulnerable particularly d/Deaf and disabled victims.

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[580] Ibid, paragraph 6.55, p.148.

[581] Ibid, paragraph 6.68, p.152.

[582] Ibid, paragraph 6.69, p.152.

[583] Ibid, paragraph 6.117, p.165.

[584] DoJ (2021): Review of Hate Crime Legislation in Northern Ireland: Departmental Response Annex A (accessed 12 December 2021).

The Department has referred to complexities associated with the third threshold and committed to undertake further work regarding the impact of the inclusion of this threshold[585].

The Department of Justice is taking forward work on hate crime legislation based on Judge Marrinan's Independent Review of Hate Crime Legislation (2020)[586]. NI has a limited bolt on provision to enhance sentences for perpetrators of hate crime. For example, if a person is convicted of assault their sentence can be increased if the crime was proven to be motivated by hate. The failure of this approach have been widely documented[587]. The hate element of motivation is frequently dropped from cases before they reach court. Northern Ireland lacks legislation which records hate crime in and of itself[588]. Recommendations proposed by Judge Marrinan will consolidate all hate-related law into one piece of legislation and as a result hate crimes would be legally recorded and prosecuted as hate crimes[589].

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[585] Ibid, paragraph 6.

[586] Ibid.

[587] Newsletter (2020): Senior judge targets NI's 'dismal' record on stopping hate crime (accessed 31 January 2022).

[588] Northern Slant (2020): Hate Crime in Review (accessed 31 January 2022).

[589] DoJ (2021): Review of Hate Crime Legislation in Northern Ireland: Departmental Response Annex A (accessed 12 December 2021).

Some progress has been made in improving legal support for victims, witnesses and alleged perpetrators of crime with a disability through legislation[590]; the development of codes of practice including a Victims Charter[591]; the introduction of special measures in the justice system, including a registered intermediary pilot scheme[592]; the appointment of a disability hate crime advocate [593] to address the underreporting of disability hate crime; and commissioning of research[594].

The Criminal Evidence (Northern Ireland) Order 1999[595] and Justice Act (NI) 2011[596] contain provisions to enable disabled people to provide evidence through intermediaries as witnesses and defendants. However, research has demonstrated that intermediaries are not widely used,[597] and a significant proportion of vulnerable and intimidated witnesses have been excluded from the use of special measures[598].

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[590] Byrne, B, et al. (2014):UNCRPD: Shortfalls in public policy and programme delivery in Northern Ireland relative to the Articles of the UNCRPD (2014), p90, ECNI.
[591] DoJ (2019): Victim Charter (accessed 11 October 2021).
[592] DoJ (2019): Northern Ireland Registered Intermediary Scheme .
[593] NI Direct (No Date): Hate Crime Advocacy Co-ordinator.
[594] Jarman, N. (2012): 'Criminal Justice Responses to Hate Crime in Northern Ireland', Belfast: Institute for Conflict Research.
[595] The Criminal Evidence (Northern Ireland) Order 1999.
[596] Justice Act (Northern Ireland) 2011 (accessed 31 January 2022).
[597] IMNI (2017): UNVRPD Jurisdictional 'Parallel' Report on Implementation in Northern Ireland: Working Paper, p.22.
[598] It is estimated that fewer than half of all vulnerable and intimidated witnesses are identified. Criminal Justice Inspectorate NI (2012): The use of special measures in the criminal justice system in Northern Ireland, p. vii (accessed 2 November 2021).

The fear of being stigmatised remains a valid concern for disabled people. Article 13.2 of the UNCRPD requires that State Parties promote training for people working within the criminal justice system, including police officers[599]. The provision of such training is recognised as a key component underpinning the realisation of the right to justice[600]. Training is an effective measure to address stigma and promote ways to address barriers of access to justice[601].

The importance of addressing attitudinal barriers was recognised in the Office of the United Nations High Commissioner for Human Rights (2017) report on the right to access to justice under article 13 of the Convention on the Rights of Persons with Disabilities[602].

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[599] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 13.2 (accessed 4 November 2021).

[600] Grant, E. and Neuhaus, R. (2012): Liberty and Justice for all: The Convention on the Rights of Persons with Disabilities, ILSA Journal of International and Comparative Law, 19, 347.

[601] Ruiz, J. and Miller, C. (2004): An exploratory study of Pennsylvania police officers' perceptions of dangerousness and their ability to manage persons with mental illness, Police Quarterly, 7(3), 359, 367.

[602] Office of the United Nations High Commissioner for Human Rights (27 December 2017): Right to access to justice under article 13 of the Convention on the Rights of Persons with Disabilities, A/HRC/37/25.

The UNCRPD notes the importance of training to address barriers in accessing justice to combat prejudices and stereotypes associated with d/Deaf and disabled people in the Justice System[603]. The need for education and training is also recognised within Article 8 which requires States to engage in awareness raising activities regarding the rights of d/Deaf and disabled people[604].

There are challenges associated with the identification of disability when d/Deaf and disabled people engage with Justice System and are held in custody[605]. A person who is arrested may have undiagnosed mental health issues or had previous contact with mental health services. Individuals may also be afraid to disclose their condition due to fear of stigmatisation[606].

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[603] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 13.2 (accessed 4 November 2021).

[604] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 8 (accessed 4 November 2021).

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

[606] Cummins, I. (2007): Boats against the current: vulnerable adults in police custody, The Journal of Adult Protection, 9 (1), 15.

Research conducted in England and Wales illustrates that questions such as ‘do you have a mental illness” were unlikely to elicit a true response, with challenges particularly highlighted with regard to a custody setting[607].

As noted above, children under the age of 16 have not been included within the Mental Health Capacity Act 2016. The Department of Health have indicated that a stand-alone project would be established to consider children with disabilities, which was to be developed as part of the review of the Children (NI) Order 1995[608]. At the time of writing there was no evidence of the development of proposals which wouldoffer children and young people new legal protections.

In the Galo[609] case, the Court of Appeal found that the Industrial Tribunal failed to make reasonable adjustments for a person with a disability and that the applicant did not receive a fair hearing. The Court noted that the Tribunal did not have regard to the Equal Treatment Bench Book (ETBB), which inter alia sets out adjustments to court or trial procedures which may be required to accommodate the needs of persons with disabilities[610].

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[607] Her Majesty’s Inspectorate of Constabulary (2015): The welfare of vulnerable people in police custody, p.15, HMIC.

[608] The Children (Northern Ireland) Order 1995

[609] Galo -v- Bombardier Aerospace UK [2016] NICA 25

[610] Ibid, para 61: ‘it is a matter of great concern that no reference appears to have been made to the ETBB (the Equal Treatment Bench Book).’

The Disability Strategy Expert Advisory Panel has proposed the following recommendations:

- 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;
- 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;
- d/Deaf people should be facilitated to fulfil their role as a member of the jury when called and should be 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. d/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[611].

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[611] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, pp.100-101 (accessed 10 October 2021).

Article 14: Liberty and security of person

Article 14 states that disability should not be a basis for detention. Laws permitting detention are incompatible with the UNCRPD[612].

The UNCRPD Committee, in its (2017) concluding observations, has raised concerns regarding legislation which provides for involuntary, compulsory treatment and detention both inside and outside hospitals on the basis of actual or perceived impairment.

The Committee recommends the repeal of legislation and practices which authorise involuntary, non-consensual, compulsory treatment and detention of people with disabilities on the basis of perceived or actual disability and that appropriate measures are taken to investigate and eliminate all forms of abuse of people with disabilities in institutional facilities[613].

d/Deaf and disabled people within Northern Ireland continue to be denied liberty within institutions and residential settings including psychiatric hospitals and care homes[614].

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[612] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 14 (accessed 4 November 2021).

[613] 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, paragraphs 34 and 35 (accessed 3 November 2021).

[614] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.37 (accessed 10 October 2021).

This is further addressed under commentary with respect to Article 15[615]: Freedom from torture or cruel, inhuman, or degrading treatment or punishment.

The Mental Health Capacity Act 2016 allows for people over 16 to be deprived of liberty in cases in which they are deemed to lack capacity due to an impairment or disturbance in the functioning of the mind or the brain. The language used in the 2016 Act represents disability-based discrimination as it refers to 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[616].'

This is non-compliant with the anti-discrimination provisions of Article 5[617], specifically in its restriction of mental incapacity to those who have "an impairment of, or a disturbance in the functioning of the mind or brain"[618] and fails to satisfy Article 12[619] which requires safeguards to

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[615] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 15 (accessed 4 November 2021).

[616] Mental Capacity Act (Northern Ireland) 2016, Part 1.

[617] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 5 (accessed 4 November 2021).

[618] Mental Capacity Act (Northern Ireland) 2016, Part 1.

[619] UN General Assembly, Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 12 (accessed 4 November 2021).

ensure the respect for the rights, will and preferences of disabled people[620].

The Disability Strategy Expert Advisory Panel has proposed the following recommendations:

- 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 the application of the 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;

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[620] Essex Autonomy Project (2015): Preliminary Analysis of the CRPD Compliance of the NI Mental Capacity Bill, p2 (accessed 29 December 2021).

- commission further research into experiences of d/Deaf and 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 the National Preventative Mechanism’s work in NI regarding the deprivation of liberty of d/Deaf and disabled people in residential and forensic settings[621].

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[621] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.57 (accessed 10 October 2021).

Article 15: Freedom from torture or cruel, inhuman, or degrading treatment or punishment

Article 15[622] states that no-one should be subjected to torture, or to cruel, inhuman or degrading treatment or punishment. Furthermore, the Article requires that no one shall be subjected to medical or scientific experimentation without free consent. Article 15 requires that State Parties should take all effective legislative and other measures to prevent d/Deaf and disabled people from being subjected to torture or cruel or degrading treatment or punishment[623].

The UNCRPD Committee, in its (2017) concluding observations, expressed concern about the continued use of physical, mechanical, and chemical restraint including the use of Taser guns and similar weapons, on people with disabilities noting the impact upon persons with psychosocial disabilities in prisons, the youth justice system, education and healthcare settings.

The Committee also expressed concerns regarding the use of segregation and seclusion. Furthermore, the Committee highlighted concerns regarding the disproportionate effect of such measures on d/Deaf and disabled members of the Black and Minority Ethnic

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[622] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 15 (accessed 4 November 2021).

[623] Ibid.

community (BME). The Committee also noted the absence of a unified strategy to address these matters or to review practice.

The Committee raised concerns regarding the use of non-consensual electroconvulsive therapy (ECT), particularly in NI. The Committee recommended the adoption of measures to eradicate the use of constraint related to disability in all settings; the prevention of the use of Taser guns; and the end of practices of segregation and isolation which amount to torture or inhuman or degrading treatment. The Committee have called for the State Party to establish strategies to identify and prevent the use of restraint for children and young people with disabilities.

The Committee has also sought the implementation of the outstanding recommendations outlined in the February 2015 report of the Inquiry by the Equality and Human Rights Commission entitled “Preventing Deaths in Detention of Adults with Mental Health Conditions”; actions to prohibit the use of non-consensual ECT on the basis of disability; and ensure that safeguards are in place which are based upon the human rights model together with effective monitoring especially in NI[624].

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[624] 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, paragraphs 36 and 37 (accessed 3 November 2021).

Juan Mendez, the United Nations Special Rapporteur on Torture, has called for a ban on the use of restraint in health care settings because of its adverse effects:

> “*Any restraint on people with mental disabilities for even a short period of time may constitute torture and ill-treatment. It is essential that an absolute ban on all coercive and non-consensual measures, including restraint and solitary confinement of people with psychological or intellectual disabilities, should apply in all places of deprivation of liberty, including in psychiatric and social care institutions.*
>
> *The environment of patient powerlessness and abusive treatment of persons with disabilities in which restraint and seclusion is used can lead to other non-consensual treatment, such as forced medication and electroshock procedures*”[625].

These statements can be viewed as interpretations of international human rights law and as such are not legally binding in the domestic context. They serve as an important reminder that the use

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[625] Special Rapporteur on Torture (2013): Report of the special rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment, Human Rights Council (A/HRC/ 22/53, 1 February 2013), paragraph 63.

of seclusion and restraint breaches human rights[626].

Resettlement

On 17 February 2021, 593 patients were being treated as inpatients in mental health hospitals in Northern Ireland. 75.5% (448) had been resident in the hospital for less than six months, whilst 1.2% (7) had been resident for 10 years or more.

Between 2015 and 2020, the number of patients being treated as inpatients in mental health hospitals decreased by 49 (7.6%) from 642 to 593[627].

The Bamford Review's ' (2005)[628] was a key direction-setting report and aimed to bring equality for learning disabilities to the fore. A range of Departmental Action Plans followed the Bamford Review reports, the most recent being Bamford Action Plan 2012-2015[629]. Action 13[630] to resettle all long-stay patients and close all long-stay hospitals by 2015 has yet to be met, with 7 in-patients remaining in mental health hospitals for longer than 10 years.

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[626] McSherry, B. (2017): Regulating seclusion and restraint in health care settings: The promise of the Convention on the Rights of Persons with Disabilities, Int J Law Psychiatry.

[627] DoH (2019): Mental Health and Learning Disability Inpatients 2020-21, Table 1.1 (accessed 30 December 2021).

[628] DoH (2005): Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland (accessed 30 December 2021).

[629] DoH (2012): Delivering the Bamford Vision: Action Plan 2012-2015 (accessed 30 December 2021).

[630] Ibid, p.37.

Muckamore Abbey

Muckamore Abbey is a hospital in Northern Ireland that provides inpatient, assessment, and treatment facilities for people with severe learning disabilities and mental health needs, forensic needs, or challenging behaviour[631]. Concerns regarding resettlement from the hospital have been prominent since 2010[632]. Allegations of abuse at Muckamore Abbey Hospital (MAH) in 2017 stimulated public outcry and resulted in criminal investigations[633] and a public inquiry[634]. The BBC reported that five vulnerable patients were assaulted by staff at MAH between 2014 and 2017[635]. In response to a Freedom of Information (FoI) request sent by BBC News NI, the Belfast Health and Social Care Trust confirmed that between 2014 and 2017 there had been more than 50 reported assaults on patients in the hospital by staff, with five investigated and substantiated[636].

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[631] HSC (ND): Muckamore Abbey Hospital (accessed 30 December 2021).

[632] Matthews, A (2015): Case Study: Law Centre for Northern Ireland Litigation in Respect of Resettlement into the Community (Muckamore Abbey) (accessed 30 December 2021).

[633] Seanín Graham (2018): Police probing more than 70 allegations of 'ill treatment' at Muckamore hospital, Irish News, 15 August 2018 (accessed 20 October 2020).

[634] DoH (2020): Swann announces Public Inquiry into Muckamore Abbey Hospital (accessed 20 October 2021).

[635] BBC (2019): Muckamore Abbey Hospital: Timeline of abuse allegations (accessed 14 December 2021).

[636] BBC (2019): Muckamore Abbey Hospital: Timeline of abuse allegations (accessed 14 December 2021).

In December 2018, 13 members of nursing staff had been suspended and two senior managers were on long-term sick leave[637]. The Review, ‘A Way to Go’[638] was commissioned by the Trust to examine safeguarding at the hospital between 2012 and 2017. The report's authors included Dr Margaret Flynn, who oversaw the review into the 2012 Winterbourne View[639] hospital scandal in England. The report concluded that patients' lives had been compromised at MAH; staff did not follow safeguarding protocols; and that CCTV footage showed patients being harmed by staff. The review found that a seclusion room in the hospital was not monitored. This led to 19 precautionary staff suspensions and a large police investigation. A team of staff was commissioned to view over 5,000 hours of CCTV images[640]. The report documented that:

- people’s lives at the hospital are characterised by inactivity and boredom;
- hospital patients are significantly likely to be harmed by their peers;

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[637] BBC (2019): Muckamore Abbey Hospital: Timeline of abuse allegations (accessed 14 December 2021).
[638] HSC BHST (2019): Summary of ‘A Review of Safeguarding at Muckamore Abbey Hospital – A Way to Go (accessed 14 December 2021).
[639] Department of Health (2013): Winterbourne View Hospital: Department of Health review and response (accessed 14 December 2021).
[640] Ibid.

- a typical response to allegations of abuse made by patients about staff is 2:1 “observations.” These create a demand for additional staff amounting to paying 50 more members of staff every week (50 whole time equivalents);
- advocacy was typically absent from considerations of safeguarding[641].

In January 2019 Professor Roy McClelland, Chair of the Bamford Review, stated that the crisis at MAH could be the tip of the iceberg and that testimonies from parents of adult children with learning difficulties were a disturbing listen[642].

In September 2019 Northern Ireland Secretary Julian Smith apologised for the pain caused to families by the situation at MAH, during a meeting with the father of one of the patients, indicating that he would take advice about ordering a public inquiry[643].

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[641] Ibid.

[642] BBC (2019): Muckamore Abbey Hospital: Problems 'could be tip of iceberg (accessed 14 December 2021).

[643] BBC (2019): Muckamore: Secretary of state to take advice on public inquiry (accessed 14 December 2021).

In October 2019, Dr Margaret Flynn called for the hospital to close[644]. Reports emerged that the Belfast Health Trust had spent £4mn on agency staff to cover vacancies at MAH[645]. Agency nurses were drafted in from England and other areas to care for patients with rates of pay of £40 compared to local rates of £9 per hour[646].

The Health Minister announced his intention to establish a Public Inquiry into MAH on 8 September 2020[647]. It was announced in June 2021 that the inquiry will be chaired by Tom Kark QC[648],who played a key role in the 2010 inquiry into avoidable deaths at Stafford Hospital in England[649].

The Inquiry commenced on 11 October 2021[650]. The core objectives of the inquiry are to:

- examine the issue of abuse of patients at Muckamore Abbey Hospital (MAH);

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[644] BBC (2019): Muckamore Abbey Hospital: Timeline of abuse allegations (accessed 14 December 2021).

[645] BBC (2019): Muckamore Abbey Hospital: Belfast Trust spends £4m on vacancies (accessed 14 December 2021).

[646] BBC (2019): Muckamore Abbey Hospital: Timeline of abuse allegations (accessed 14 December 2021).

[647] DoH (2020): Muckamore Abbey Hospital - Public Inquiry (accessed 30 December 2021).

[648] BBC (2021): Muckamore Abbey Hospital: Public inquiry terms of reference announced (accessed 30 December 2020).

[649] BBC (2013): Stafford Hospital: Q and A (accessed 30 December 2021).

[650] BBC (2021): Muckamore Abbey Hospital: Public inquiry terms of reference announced (accessed 30 December 2020).

- determine why the abuse happened and the range of circumstances that allowed it to happen;
- ensure that such abuse does not occur again at MAH or any other institution providing similar services in Northern Ireland[651].

The Inquiry will report and make findings on events that occurred between 2nd December 1999 and 14th June 2021[652].

The extent of reported abuse at MAH raises questions as to the degree to which d/Deaf and disabled people have been protected from torture or cruel, inhumane, or degrading treatment or punishment. Taking all this into account, it is unlikely that the Northern Ireland Executive is meeting the requirements of Article 15[653].

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[651] Muckamore Abbey Hospital Inquiry (2021): Terms of Reference, paragraph 1 (accessed 30 December 2021).

[652] Ibid, paragraph 2.

[653] UN General Assembly: Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106, Article 15 (accessed 4 November 2021).

Dunmurry Manor

Dunmurry Manor is a 76-bed residential and nursing home located in Dunmurry, Belfast, owned and operated by Runwood Homes Limited (Runwood). Specialising in dementia care, the home opened in 2014. In November 2016 the Regulation, Quality, and Improvement Authority (RQIA) issued three notices of Failure to Comply which set out the actions required by Dunmurry Manor to achieve compliance with Nursing Home Regulations by early January 2017 within a period of 90 days. Families approached the Commissioner for Older People Northern Ireland (COPNI) to express significant misgivings about the standards of care at the home in 2016. They reported that the care provider, the Regulation and Quality Improvement Authority (RQIA), the Health and Social Care Trusts (HSCTs) and the Patient and Client Council (PCC) had not addressed their complaints and they had nowhere else to go. In response, the COPNI utilised investigation powers. 'Home Truths: A Report on the Commissioner's Investigation into Dunmurry Manor Care Home' was first published in June 2018 and was critical of the practice of adult safeguarding making the case for safeguarding legislation[654].

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[654] COPNI (2018): Home Truths: A Report on the Commissioner's Investigation into Dunmurry Manor Care Home (accessed 26 March 2022).

The investigation reported the following findings:

- an environment of poor care and treatment;
- serious safeguarding issues and medicines management issues, compounded by a failure of responsible bodies (RAs) to act quickly and comprehensively;
- evidence of physical and sexual assaults on female residents;
- Residents leaving the home unnoticed and multiple instances of inhuman and degrading treatment;
- despite Dunmurry Manor being regulated against care home standards within a regime of regulation and inspection, harm still occurred[655].

The conclusion of the review was published in January 2020[656]. The Commissioner called for:

- the development and implementation of an Adult Safeguarding Bill;
- stronger financial penalties for providers who don't meet minimum standards of care;
- a ratings system for care homes;
- changes to complaints systems to identify the roles and responsibilities of authorities in handling complaints;

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[655] Ibid, p.8.

[656] COPNI (2020): Commissioner for Older People concludes his Home Truths investigation into Dunmurry Manor Care Home (accessed 15 December 2021).

- the establishment of an independent body to encourage and support whistle-blowers; dementia friendly standards to hygiene and cleanliness of care settings[657].

The Adult Safeguarding Bill

The Health Minister Robin Swann pledged to bring forward a new Adult Safeguarding Bill for Northern Ireland, to help protect care home residents and other vulnerable people[658]. The draft bill defines an adult at risk as:

a) a person aged 18 or over;

b) a person whose exposure to harm through abuse, neglect or exploitation may be increased by their personal characteristics and/or life circumstances;

c) a person who is unable to protect their own well-being, property, assets, rights, or other interests;

d) cases where the action or inaction of another person or persons is causing, or is likely to cause, him/her to be harmed[659].

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[657] COPNI (2019): Summary of responses to Home Truths recommendations Collated by COPNI - December 2019 (accessed 15 December 2021).

[658] DoH (2020): Minister announces plans for Adult Safeguarding Bill for Northern Ireland (accessed 15 December 2021).

[659] DoH (2021): Adult Protection Bill – Draft Final Policy Proposals for Ministerial Consideration (July 2021), paragraph 2 (accessed 15 December 2021).

The draft Bill will set out Principles which should be adhered to by everyone involved in adult safeguarding and protection, these include:

- prevention;
- autonomy;
- empowerment;
- dignity;
- proportionality;
- partnership and accountability[660].

The draft bill will:

a) place a statutory duty on the Health and Social Care (HSC) Trusts, PSNI, HSC Board, Public Health Agency (PHA), Regulation and Quality Improvement Authority (RQIA) and independent providers commissioned or contracted to provide health and social care services to report to the relevant HSC Trust any cases where there is a reasonable cause to suspect that an adult meets the criteria of risk and in need of projection[661];

b) place a statutory duty on HSC Trusts to follow up enquiries into all cases where someone who is suspected of being an adult at risk and in need of protection' is brought to its attention[662];

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[660] Ibid, paragraph 3.

[661] Ibid, paragraph 4.

[662] Ibid, paragraph 5.

c) introduce a power of entry[663];

d) introduce a statutory provision of independent advocates who can assist adults at risk to be involved in and influence decisions taken about their care[664];

e) establish the Independent Adult Protection Board and place it on a statutory footing[665];

f) introduce Serious Case Reviews (SCRs) which are multi-agency reviews that will investigate the circumstances surrounding the death of, or serious harm to, an adult at risk and in need of protection[666];

g) place a statutory duty on HSC Trusts, Police Service of Northern Ireland (PSNI), Probation Board for NI, HSC Board, Public Health Agency, RQIA and independent providers commissioned or contracted to provide health and social care services to cooperate with both HSC Trusts and PSNI when those bodies are making enquiries into a case where there is reasonable cause to suspect that an adult meets the criteria of ‘an adult at risk and in need of protection’. This includes the provision that organisations required

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[663] Ibid, paragraph 6.

[664] Ibid, paragraph 7.

[665] Ibid, paragraph 8.

[666] Ibid, paragraph 9.

to co-operate do not have to do so in instances in which doing so would conflict with the exercise of their function[667];

h) a new power to access financial records where there is suspected financial abuse[668];

i) introduce new offences of ill-treatment and wilful neglect. This includes a care worker offence and a care provider offence[669].

While the draft Bill is welcome, it refers to a rights-based approach in the context of promoting and respecting dignity - it does not reflect a human rights approach. It would be strengthened if it adopted a human rights-based approach benchmarking against the FREDA principles of fairness, respect, equality, dignity, and autonomy and clarifying that the Bill incorporates the full range of human rights standards ratified by the UK[670].

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[667] Ibid, paragraph 10.

[668] Ibid, paragraph 11.

[669] Ibid, paragraph 12.

[670] NIHRC (2021): NIHRC response to the Department of Health's consultation on legislative options for an adult protection bill in Northern Ireland (accessed 15 December 2021).

Electro Convulsive Therapy (ECT)

Electroconvulsive therapy (ECT) is employed as a treatment for some types of severe mental illness that have not responded to other treatments[671]. An anaesthetic and muscle relaxant are given, and then an electric current is passed across the patient's head. This causes a controlled fit, which typically lasts less than 90 seconds. 123 patients received ECT between 1 of April 206 and 31 March 2017[672]. 52%[673]of courses of ECT were given on a voluntary basis, indicating that 48% were not voluntary and therefore lacked consent[674].

The most common primary indication for the administration of ECT was reported as the severity of the mental state of the patient, followed by non-responsiveness to medication and inadequate eating and drinking. Depressive disorder continues to be the diagnostic group which requires the majority of ECT courses. ECT is also very occasionally used in the management of treatment resistant mania and schizoaffective disorder[675]. During 2016/17, 68% of patients receiving ECT were female[676].

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[671] RCPsyh (ND): Electroconvulsive therapy (ECT) (accessed 29 December 2021).

[672] RQIA (2017): Annual Report on the Administration of Electroconvulsive Therapy in Northern Ireland, p.4 (accessed 29 December 2021).

[673] Ibid.

[674] Ibid.

[675] Ibid, p.9.

[676] Ibid.

The number of courses of ECT administered to detained patients between 2014 and 2017 has been increasing. In 2014/15 year 38.6% of courses of ECT were administered to detained patients, 31.4% in 2015/16 and 47.5% in 2016/17[677]. The majority of courses during 2016/17 had either a diagnosis of Depressive Episode (44%) or Recurrent Depressive Disorder (28%)[678].

Concerns have been raised about the oversight of electroconvulsive therapy (ECT) in Northern Ireland[679]. Northern Ireland has six ECT clinics – one of these - Altnagelvin Area Hospital - is not a member the Electroconvulsive Therapy Accreditation Service (ECTAS). The Western Health and Social Care Trust said Altnagelvin Hospital was taking "preparatory work" to apply in spring 2022. It said delays were due to maintenance within the hospital estate and the Covid-19 pandemic.

ECT clinics at Holywell Hospital in Antrim and Belfast's Mater Hospital are members of the ECTAS scheme but their accreditation has expired. Holywell's ECT clinic was reviewed in October 2021, and it is awaiting a decision on whether it will be accredited again. The Mater Hospital's review was delayed because of the pandemic and has been rearranged for June 2022[680].

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[677] Ibid, p.10.

[678] Ibid, p.12.

[679] BBC (2021): Concerns over regulation of electroconvulsive therapy in NI.

[680] Ibid.

The Use of Restraint in Healthcare Settings

Restraint continues to be used in NI in both Education and Health Care Settings. The consequences of the use of restraint have been reported as overwhelmingly negative and detrimental, associated with immediate escalation of distress, and intense feelings such as despair, shame, terror, and rage[681]. Using seclusion and restraint also risks re-traumatizing those who have suffered prior violence and abuse.

There is growing evidence that those with disabilities are more likely to experience violence in their lives than those without disabilities. Two meta-analyses have estimated that children and adults with disabilities are more likely to experience interpersonal violence than those without disabilities[682].

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[681] Chan, J., LeBel, J. and Webber, L. (2012): The dollars and sense of restraints and seclusion, Journal of Law and Medicine, 20, pp 73–81.

[682] Hughes K., Bellis M.A., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton, C., Shakespeare, T. and Officer, A. (2012): Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies, Lancet. 28;379 (9826):pp 1621-9.
Jones, L., Bellis, M.A., Wood, S., Hughes, K., McCoy, E., Eckley, L., Bates, G., Mikton, C., Shakespeare, T. and Officer, A. (2012): Prevalence and risk of violence against children with disabilities: a systematic review and meta-analysis of observational studies. Lancet. 8; 380 (9845): 899-907.

Studies have indicated that the use of seclusion and restraint can exacerbate mental health issues and distress[683]. Those who have been secluded or restrained have been vocal regarding the negative impact and harm caused by the use of such interventions[684].

The Equality and Human Rights Commission describes the practice of restraint as 'an act carried out with the purpose of restricting an individual's movement, liberty and/or freedom to act independently'.[685] There is no specific data regarding the use of restraint and seclusion in Northern Ireland. However, the experience of Disability Action is that whilst use of physical restraint may have decreased, and there are relevant safeguarding policies and procedures in place, the use of chemical restraint is still ongoing and of concern. The recording of restrictive interventions is recognised internationally as a critical means of ensuring that any practice is human rights compliant and appropriately monitored and scrutinised[686].

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[683] Chieze, M., Hurst, S., Kaiser, S. and Sentissi, O. (2019): Effects of Seclusion and Restraint in Adult Psychiatry: A Systematic Review. *Front Psychiatry*. 10:491.

[684] Chan, J., LeBel, J. and Webber, L. (2012): The dollars and sense of restraints and seclusion. Journal of Law and Medicine, 20, pp. 73–81.

[685] Equality and Human Rights Commission (2019): Human rights framework for restraint: principles for the lawful use of physical, chemical, mechanical and coercive restrictive interventions, London: EHRC.

[686] Children and Young Peoples Commissioner Scotland (2018): No Safe Place: Restraint and Seclusion in Scotland's Schools, Edinburgh: Children and Young People's Commissioner.

The Minister for Health Robin Swann launched a 12-week consultation on a draft policy on the use of restrictive practice in health and social care settings[687]. The draft policy provides the regional framework to integrate best practice in the management of restrictive interventions, restraint, and seclusion across all areas where health and social care is delivered in Northern Ireland. The emphasis is on minimising the use of restrictive practices and providing clear guidance to ensure best practice when used[688].

The aim of the policy is to reduce the use of restraint and seclusion and to apply a monitoring and assurance role to the RQIA which includes reviewing the implementation of rights-based approach for individuals and minimisation measures[689]. This policy is not fully compliant with the UNCRPD which has an emphasis upon identifying and ending the use of restraint.

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[687] DoH (2021): Public Consultation on Regional Policy on the Use of Restrictive Practices in Health and Social Care Settings (accessed 14 December 2021).

[688] DoH (2021): Regional Policy on the use of Restrictive Practices in Health and Social Care Settings And regional operational procedure for the use of Seclusion: Consultation Version (accessed 14 December 2021).

[689] Ibid, p.2, pp.6-7.

The Use of Restraint in Education

There is no legal requirement for schools in NI to record incidents of restraint and seclusion. A joint research study carried out by the charities Challenging Behaviour Foundation (CBF) and Positive Behaviour Support Scotland (PBSS), attempted to assess the use of restrictive practices on children with additional needs in schools across the UK, including Northern Ireland[690]. The research included a survey carried out by CBF with 204 parents whose children have additional needs, as well as analysis of 566 case studies of families being supported by PBSS gathered over a 12-month period. The survey revealed that:

- 88% of parents reported that their child had been restrained in school with 35% stating this happened on a regular basis;
- 71% of families reported that their child had been secluded in school, with 21% stating this was happening on a daily basis;
- 50% of respondents' children had been prescribed medication specifically to manage challenging behaviour.

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[690] The Challenging Behaviour Foundation (2019): Reducing Restrictive Intervention of Children and Young People Case study and survey results, January 2019, Chatham: The Challenging Behaviour Foundation.

Although there is no Northern Ireland-specific research on the use of restrictive interventions in school settings, the Northern Ireland Commissioner for Children and Young People (NICCY) has stated an awareness of seclusion and restraints being used with children with special educational needs, to address behavioural challenges. They have also been informed of some cases of seclusion being used as ‘in school’ or ‘informal’ suspensions for breaches of uniform rules[691].

In 2019 the British Association of Social Workers Northern Ireland (BASW NI) released a policy statement expressing concern at the lack of standardised guidance from the Department of Education (DE) regarding the use of restriction and seclusion with children and young people who have additional needs[692]. This statement coincided with several high-profile reports revealing the widespread and largely unmonitored use of both practices in schools across the UK.

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[691] Children and Young People’s Commissioner Scotland, Children’s Commissioner for Wales and the Northern Ireland Commissioner for Children and Young People (No Date): Joint submission to the United Nations Committee Against Torture 66th session on the sixth Periodic Report of the United Kingdom of Great Britain and Northern Ireland by the Scotland, Wales and Northern Ireland Children and Young People’s Commissioners, paragraph 6.4 (accessed 5 November 2021).

[692] BASW (NI) (2021): BASW NI policy statement concerning restraint and seclusion of children and young people in schools and educational facilities (accessed 30 December 2021).

As a result of these reports and sustained campaigning from charities and parent groups, the English Government introduced a new framework in 2019 aimed at reducing reliance on restriction and seclusion in educational settings, with Scotland and Wales also expected to release similar frameworks.

The increasing focus on the use of restrictive practices in schools also comes at a time when the number of children with additional needs are growing. The use of physical contact by education staff in classrooms is guided by the principle of 'reasonable force' and is governed under Article 4 of the Education (Northern Ireland) Order 1998[693]. The Order is based on the principle that the need to use reasonable force to restrain or control a pupil should be rare. However, where a pupil's behaviour threatens the safety of other pupils and staff, a member of staff may use such force as is reasonable in the circumstances to prevent the pupil from:

- committing an offence;
- causing personal injury to, or damage to the property of, any person (including the pupil him/herself);

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[693] Article 4 of the Education (Northern Ireland) Order 1998 (accessed 5 November 2021).

- engaging in any behaviour prejudicial to the maintenance of good order and discipline at the school or among any of its pupils, whether during a teaching session or otherwise[694].

All schools have a statutory responsibility under Articles 3-6 of the Education (Northern Ireland) Order 1998 for developing their own good behaviour and discipline policies, including any sanctions that may be taken[695]. A survey by the Northern Ireland Committee of the Irish Congress of Trade Unions (ICTU NIC) of 1427 teaching and support staff on their experience of violence in the classroom in 2019 indicates variable use and knowledge of behaviour policies at a school level[696].

In 2017, the Westminster Department of Health and Social Care (DHSC) and the Westminster Department for Education (DfE) launched a joint consultation on a set of draft guidelines aimed at reducing reliance on restrictive interventions in special education, and in health and care settings that care for children and young people.

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[694] Ibid, Part II Article 4.

[695] Ibid, Articles 3-6.

[696] NIC-ICTU (2019): An Acceptable level of violence? (accessed 5 November 2021).

The purpose of the guidelines was to ‘help special education, and health and care settings develop plans to support children and young people whose behaviour challenges, to reduce the incidence and risk associated with that behaviour and promote and safeguard the welfare of children and young people in their care’[697].

The finalised guidelines ‘reducing the need for restraint and restrictive intervention’ were published in 2019[698]. The guidelines were subject to criticism noting that the guidance is non-statutory and:

- does not cover mainstream schools where a significant number of restrictive practices take place;
- does not require schools to inform parents if a restrictive intervention has occurred;
- defends the use of restrictive practices such as seclusion rooms ‘as a disciplinary penalty;
- does not include an accompanying training programme in alternative methods included;

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[697] Dept of Education (2019): Restraint in mainstream settings & alternative provision.

[698] HM Government (2019): Reducing the Need for Restraint and Restrictive Intervention Department of Education and Department of Health.

- fails to prohibit the use of prone restraint (prohibited in adult care)[699].

The Equality and Human Rights Commission published the final report of the review into the use of restraint in schools in Great Britain in July 2021[700]. The purpose of the inquiry was to consider:

- whether and how schools are collecting, recording, and using data on their use of restraint and restrictive interventions;
- what schools can learn from places that routinely record, monitor, and analyse this data and use it to make changes to their approach.

The report concluded that restraint in schools should be monitored, recorded, and analysed with the same rigour as school exclusions, to give greater understanding of:

- how, where why and when restraint is used;
- how its use can be minimised.

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[699] Hattenstone, S., Allison, E (2019): ‘He was covered in bruises’: the vulnerable children being harmed in special schools’, The Guardian, 6th July 2019 (accessed 5 November 2021).

[700] EHRC (2021): Inquiry: how schools are monitoring the use of restraint (accessed 5 November 2021).

The report emphasised the importance of schools understanding:

- what constitutes restraint;
- what they should record;
- how analysis can help support pupils and staff.

The Department of Education NI (DENI) produced revised interim guidance on the use of restraint and seclusion in May 2021[701]. The purpose of the guidance was to remind educational settings that reasonable force/restraint should only be used as a last resort. The guidance requires that all instances of restraint should be recorded, and that parents and carers should be informed. The guidance requires that follow up support is provided to pupils and staff. The Department indicated that a review of the use of restraint was being undertaken and a working group was established which was supported by a reference group. At the time of writing the review had yet to be concluded.

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[701] DfE (2021): Interim guidance on use of restraint and seclusion in educational settings (accessed 5 November 2021).

The Disability Strategy Expert Advisory Panel has proposed the following recommendations:

- 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 regarding restraint and seclusion;
- assess what areas need to be strengthened, changed, or abolished;
- 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, recognise the challenges faced, provide support to change culture, custom and practice
- model existing good practice and upscale it;
- commit to establishing a clear protocol for the gathering and publication of data in respect of medications 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 resource a systemic move to therapeutic interventions[702];
- 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[703];

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[702] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations , pp.53-54. (accessed 10 October 2021).

[703] Ibid, p.60.

- increase funding and availability of independent advocacy to enable d/ Deaf and disabled people to report abuse in institutional settings[704];
- establish an independent review on informal exclusions from school in NI;
- 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[705].

The authors of this report recommend the introduction of measures to end the use of non-consensual ECT.

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[704] Ibid, p.61.

[705] Ibid, p.93.

Article 16: Freedom from Exploitation, Violence, and Abuse

Article 16 provides that the State should take all appropriate measures to protect d/Deaf and disabled people from all forms of abuse, violence, and exploitation[706]. The UNCRPD Committee raised concerns, in its (2017) concluding observations, regarding the abuse, ill-treatment, sexual violence and exploitation of women, children, intersex persons, and elderly persons with disabilities.

The Committee raised concerns regarding the levels of hate crime directed towards people with disabilities and differences in legal provisions for sentencing with respect to different categories of hate crime. The Committee recommended the following actions to be undertaken in partnership with DPOs and in line with target 16.3 of the Sustainable Development Goals:

- Measures to ensure equal access to justice and to safeguard persons with disability from abuse, ill treatment, sexual violence, and exploitation;

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[706] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 16 (accessed 4 November 2021).

- A comprehensive definition of hate crime and appropriate prosecutions and convictions;
- Measures to ensure that all facilities and programmes are effectively monitored in line with article 16 (3) of the Convention[707].

d/Deaf and disabled people are of greater risk of violence, abuse, and exploitation than people who are not disabled[708]. Hate crimes against d/Deaf and disabled people in Northern Ireland increased from 63 in 2018-19 to 86 in 2019-20[709]. These figures may not fully reflect the level of Hate Crime in the region. The Equality Commission NI have consistently highlighted the need to effectively address the under reporting of hate crime[710].

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[707] 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, paragraph 38 (accessed 3 November 2021).

[708] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.58 (accessed 10 October 2021).

[709] PSNI (2021): Incidents and Crimes with a Hate Motivation Recorded by the PSNI: Update 30th June 2021 (accessed 4 November 2021).

[710] ECNI (2020): Response to consultation: Hate Crime Legislation in Northern Ireland, Independent Review. p.55 (accessed 16 December 2021).

d/Deaf and disabled women experience disproportionate levels of domestic violence and face barriers to accessing appropriate support[711]. Women's Aid Northern Ireland report that 41% of women in refuges and 41% of women accessing outreach services have a disability[712]. The UK has not ratified the Istanbul Convention[713] which provides a legal framework to tackle numerous forms of Violence Against Women and Girls (VAWG), including domestic violence, rape, sexual assault, female genital mutilation (FGM), so-called 'honour-based' violence, and forced marriage. It has been termed the 'gold standard approach' to tackling these widespread instances of gender-based violence[714].

The potential for abuse can be greater within institutional settings as demonstrated by the launch of a Public Investigation into events at Muckamore Abbey Hospital[715] and the Older Person's Commissioner's report on Dunmurry Manor[716] both of which include evidence of violence against and the abuse of d/Deaf and disabled people.

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[711] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations. pp.59-60 (accessed 10 October 2021).

[712] Women's Aid Federation NI (2020): Annual Report 2019-2020. (accessed 2 November 2021).

[713] CUHRLS (2020): Why hasn't the UK Government ratified the Istanbul Convention eight years after signing it? (accessed 30 December 2021).

[714] UN Women (2013): Comment made by then-UN Women Deputy Executive Director, Lakshmi Puri: The Istanbul Convention: strengthening the response to ending violence against women. (accessed 30 December 2021).

[715] DoH (2020): Muckamore Abbey Hospital - Public Inquiry (accessed 2 November 2021).

[716] COPNI (2020): Commissioner for Older People concludes his Home Truths investigation into Dunmurry Manor Care Home (accessed 15 December 2021).

Whilst there is no single source of evidence on violence, exploitation, and abuse of d/Dead and disabled people within care systems in Northern Ireland[717], there is an Adult Safeguarding Policy in place for the health and social care sector. However, whilst the policy provides for protective interventions in the case of adults at risk of harm without the individual's consent[718]. The Health Minister Robin Swann pledged to bring forward a new Adult Safeguarding Bill for Northern Ireland, to help protect care home residents and other vulnerable people[719].

The Disability Strategy Expert Advisory Panel proposed the following recommendations:

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

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[717] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.59 (accessed 10 October 2021).

[718] HSC (2016): Adult Safeguarding Operational Procedures (accessed 2 November 2021).

[719] DoH (2020): Minister announces plans for Adult Safeguarding Bill for Northern Ireland (accessed 15 December 2021).

- commission further research to understand experiences of d/Deaf and disabled people in accessing domestic violence services and access legal redress;
- increase funding and availability of independent advocacy to enable d/ Deaf and disabled people to report abuse[720].

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[720] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, pp.60-61 (accessed 10 October 2021).

Article 17: Protecting the Integrity of the Person

Article 17 of the UNCRPD requires State parties to ensure that d/Deaf and disabled people have the right to respect for his or her physical and mental integrity on an equal basis with others[721]. The UN Committee on the rights of d/Deaf and disabled People raised concerns that d/Deaf and disabled People including women, intersex persons and girls and boys reportedly continue to be subjected to involuntary medical treatment including enforced sterilisation and conversion therapies.

The Committee recommended that the State Party repeal all types of legislation, regulations and practices which allow any forced intervention of surgery, in order to ensure the right to free, prior informed consent to treatment is upheld and that supported decision-making mechanisms and strengthened safeguards are provided, paying particular attention to women, intersex persons, girls, and boys[722].

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[721] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 17 (accessed 4 November 2021).

[722] 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, paragraphs 40 and 41 (accessed 3 November 2021).

The concept of personal integrity has attracted notable attention in international human rights law debates in recent times. It has been viewed of strategic importance in the realisation of fundamental freedoms and rights d/Deaf and disabled people[723]. This article concerns the right to bodily integrity and the right to consent to medical treatment. Consent is central to all forms of healthcare, including treatment leading to sterilisation.

The UNCRPD Committee has made it clear that informed consent is a core element of Article 17 while decisions of the European Court of Human Rights also support personal integrity. Forced treatment is a major problem for persons with disabilities and State Parties must indicate the measures to protect persons from coercive interventions such as forced medication, seclusion, restraint and non-consensual sterilisation.

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[723] Bantekas, I., Stein, M. A. and Anastasiou, D. (Eds.) (2018): The convention on the rights of persons with disabilities: a commentary, Oxford: Oxford Scholarly Authorities on International Law.

Issues pertaining to Article 17 have been explored within the commentary with respect to Article 11 Situations of risk and humanitarian emergencies[724], Article 12 Equal recognition before the law[725], and Article 15 Freedom from torture, cruel or inhuman or degrading treatment or punishment[726]. The Mental Health and Capacity Act (2016) provides for substituted decision making and therefore contravenes the UNCRPD[727]. The continued use of restraint[728] in the region is problematic together with the continued use of involuntary ECT[729].

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[724] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 11 (accessed 4 November 2021).

[725] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 12. (accessed 4 November 2021).

[726] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 15. (accessed 4 November 2021).

[727] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.100 (accessed 10 October 2021).

[728] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.11.2, p.21.

[729] RQIA (2017): Annual Report on the Administration of Electroconvulsive Therapy in Northern Ireland, p.4 (accessed 29 December 2021).

Article 18: Liberty of Movement and Nationality

Article 18[730] requires State parties to recognise the rights of d/Deaf and disabled people to liberty of movement, freedom to choose their residence and to a nationality on an equal basis with others. This includes ensuring that d/Deaf and disabled people have the right to acquire and change nationality and are not deprived of nationality on the basis of disability; and are not deprived of their ability to obtain, possess, and utilise documentation of their nationality or other documentation of identification or to utilise relevant processes such as immigration proceedings, that may be required to facilitate exercise of the right to liberty of movement. This includes ensuring that disabled people are free to leave any country including their own and are not deprived of their right to enter their own country.

Article 18[731] requires that children with disabilities are registered immediately after birth and shall have the right from birth to a name, the right to acquire nationality and as the right to know and be cared for by their parents.

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[730] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly Article 19 (accessed 4 November 2021).

[731] Ibid.

The UN Committee is concerned that the UK and as a consequence the NI Executive maintain their reservation to Article 18 of the Convention[732]. The reservation relates to UK immigration policy. The UK has a comprehensive set of rules and procedures for governing entry and stay in the UK and for the acquisition of citizenship. The Government believes that the UK must retain such flexibility[733].

The UK Government has been criticised for not addressing d/Deafness and Disability[734] within the 'New Plan for Immigration'[735] and for the incompatibility of the plan with human rights standards[736]. The closest possible reference to disability in the document is 'vulnerability'[737]. The UK Government has made a commitment to protecting children and vulnerable people and that resettlement schemes are specifically targeted at the most vulnerable[738].

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[732] 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, paragraph 41 (accessed 3 November 2021).

[733] UK Parliament (2009): Proposals for Reservations paragraph 64 (accessed 19 December 2021).

[734] Refugee Law Initiative (2021): Entrenching Invisibility and Creating Vulnerability: The Absence of Disability in the UK's New Plan for Immigration (accessed 20 December 2021).

[735] UK Government (2021): New Plan for Immigration: policy statement (accessible) (accessed 20 December 2021).

[736] Refugee Law Initiative (2021): Entrenching Invisibility and Creating Vulnerability: The Absence of Disability in the UK's New Plan for Immigration.

[737] UK Government (2021): New Plan for Immigration: policy statement (accessible).

[738] Ibid.

Migrants and refugees with disabilities often constitute forgotten refugees. Persons with disabilities on the move are often at risk of being abandoned during flight, as they are liable to being considered burdensome on the difficult journeys ahead. Practice in resettlement programmes indicates that refugees with disabilities can face additional barriers and are not always given equitable access on the same basis as refugees without disabilities. The absence of data about refugees with disabilities is an issue that points towards the existence of a much larger problem regarding the invisibility of persons with disabilities in immigration and asylum processes[739].

The European Court of Human Rights has acknowledged that the failure by the State to provide for d/Deaf and disabled migrants and refugees places them in situations of vulnerability[740].

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[739] Refugee Law Initiative (2021): Entrenching Invisibility and Creating Vulnerability: The Absence of Disability in the UK's New Plan for Immigration (accessed 20 December 2021).

[740] Case of M.S.S. v. Belgium and Greece (Application no. 30696/09) 21 January 2011.

Article 19: Living independently and being included in the community

> *"My understanding is that the states withdrawal of various crucial support services has had a massive impact on many disabled people's ability to live independently as has errors in PIP assessments and the withdrawal of the Independent Living Fund. Independent living includes the right to be able to go out with your mates and enjoy yourself occasionally"*
>
> **A disabled man with a long-term health condition aged 50-54.**

Article 19 requires State Parties to recognise the equal rights of d/Deaf and disabled people to live in the community with choices equal to others. States are required to take effective and appropriate measures to facilitate full enjoyment of the right of people with disabilities to full participation and inclusion in the community.

This includes ensuring that people with disabilities have the right to choose their place of residence and who they live with on equal basis with others and are not obliged to live in a particular living arrangement, the right to a range of in-home, residential and other community support services including personal care to support independent living and inclusion and to protect against isolation and segregation, and that community services and facilities are available and accessible on an equal basis to people with disabilities and responsive to the needs of people with disabilities[741].

In its (2017) concluding observations, the Committee expressed concerns as to the realisation of Article 19:

- that UK legislation fails to recognise independent living and being included the community as a human right;
- policies are in place that affect the ability to live independently such as the decrease in appropriate housing, in household income and budgets relating to independent living;
- responsibility transferred to devolved administrations for supporting independent living without providing an appropriate and specific budget;
- many d/Deaf and disabled people are still institutionalised when: they lack the financial resources to afford personal assistance; when local authorities decide that this assistance is best provided in a care home; and when the main driver of the assessments is the cost;

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[741] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 19 (accessed 4 November 2021).

- the lack of support services and accessible public facilities, including personal assistance, for d/Deaf and disabled people[742].

The UNCRPD Committee has highlighted, in its General Comment Number 5 on Independent Living[743], that persons with disabilities have been denied personal and individual choice and control across all areas of life.

This includes a lack of housing choice and the absence of support for independent living which can result in marginalisation, segregation, isolation, reliance on family and institutionalisation. Furthermore, d/Deaf and disabled people are more likely to live in poverty and to experience social exclusion which can limit freedom and result in dependence and the absence of life choices.

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[742] 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, paragraph 45 (accessed 3 November 2021).

[743] Committee on the Rights of Persons with Disabilities (2017): General comment No. 5 on living independently and being included in the community (accessed 30 December 2021).

Within the NI context specifically, there are several areas of concern:

- the lack of any definition or Strategy on Independent Living in NI.
- the closure of the Independent Living Fund to new applicants has limited d/Deaf and disabled people's choice and control[744];
- the ongoing reform of Adult Social Care needs to ensure d/Deaf and disabled people are involved at every level. The Disability Strategy Expert Advisory Panel has made a series of proposals which need to be agreed and implemented[745];
- the roll out of Self-Directed Support as a model to promote choice and control has been limited[746];
- the availability of suitable housing for people with a range of disabilities continues to be a significant issue (ranging from suitable supported living accommodation to being able to make physical changes to our homes)[747];
- people remaining in institutional care[748].

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[744] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations p.34 (accessed 10 October 2021).

[745] Ibid, p.37.

[746] Ibid, p.38.

[747] Ibid, p.34.

[748] Ibid, p.37.

Actions by Governments which undermine Article 19[749] are of serious concern. Article 19[750] cross cuts with rights to accessibility, education and health and other articles of the UNCRPD due to the interrelationship between independent living and access to opportunities and services. To date within NI there has been no statutory definition of Independent Living or a coherent strategy through which to promote Independent Living[751]. The absence of an integrated strategy for Independent Living combined with little or no co-ordination between services relating to education, childcare, transport, housing, employment and social security programmes undermines policies which if, all working together, would support deaf and disabled people to live independently. At the time of writing this issue remains unresolved.

There has been limited progress with respect to both the UK Government's and NI Executive's response to the UNCRPD Committee's recommendations concerning the rights of d/Deaf and disabled people to live independently in the community. The right to live independently is associated with access to resources and appropriate infrastructure.

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[749] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 19.

[750] Ibid.

[751] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.36 (accessed 10 October 2021).

Access to appropriate social care packages and accessible housing have been recognised as the cornerstones of independent living[752]. Scotland and Wales have been recognised as making progress through the creation of funding streams to support independent living[753]. UKIM, in their 2018 report 'Progress on disability rights in the UK', refer to a chronic short shortage of accessible homes across the UK and note that adult social care is at crisis point[754].

There is a lack of provision for accessible and affordable housing for d/Deaf and disabled people coupled with challenges in making adaptations at home[755]. Long delays in accessing housing limits the right to live independently[756]. Participants in the qualitative research informing this report have told us that they face significant challenges in accessing housing:

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[752] UKIM (2018): Progress on disability rights in the United Kingdom, p.12 (accessed 10 October 2021).

[753] Ibid, p.12.

[754] Ibid, p.12.

[755] Department for Communities (2021): NI Homelessness Bulletin (accessed 5 November 2021).

[756] They Work For You (2021): Social Housing: East Belfast, Joanne Bunting, DUP (accessed 16 December 2021).

> “*There is not enough supported housing for people. The points system is challenging as often you cannot access enough for social housing - the point system needs reviewed to recognise the needs of disabled people who can face challenges in accessing private housing.*
> *It must get to crisis point before something is done and that can be too late. It is not fair to ask families to step in and support, particularly if they are older”.*
> **Disabled carer with a long-term health condition**

Outcome 8 of the Northern Ireland Executive’s Programme for Government (PfG) Outcomes Delivery Plan: ‘We care and help for those in need’ and Outcome 9: ‘We are a shared, welcoming and confident society that respects diversity’ included a commitment to improve quality of life for d/Deaf and disabled people[757]. The identified actions for fulfilling these outcomes include ensuring that 8% of new social homes are wheelchair accessible; introducing opportunities for 200 new NI athletes in the Special Olympics; and improving understanding of British Sign Language and Irish Sign Language.

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[757] Northern Ireland Executive Office (2018): Outcomes delivery plan 2018/19. Outcome 8 (accessed 10 October 2021).

Progress was to be measured every six months, using a number of indicators set out in the draft PfG, including indicator 42[758].

Questions were raised as to whether an 8% target for new accessible social homes was reflective of demand. There were also concerns as to whether the new accessible social homes would be provided in a way that addressed demand in rural and urban areas[759]. Participants in the qualitative research which informs this report were vocal in their challenges with respect to accessible housing and securing adaptions:

> *"We have significant housing issues as a couple and one of us uses a wheelchair sometimes when having issues with artificial limbs. We got a new front door, and no one even thought of making sure it was wide enough for a wheelchair.*

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[758] Indicator 42 aims to increase quality of life for people with disabilities. The lead measure is the average life satisfaction score of people with disabilities. The Programme for Government Framework is intended to facilitate improvements in wellbeing for all people in society, addressing economic and social issues in a way that supports improvements in quality of life. The benefit of this indicator has yet to be realized.

[759] UN CRPD Independent Mechanism for NI stakeholder roundtable, Sept 2018.

> *So, when it’s fitted only to find out it’s not wide enough for a self-propelling wheelchair, when you bring it to the attention of the Northern Ireland Housing Executive you get back oh it’s a big job and they put you off getting it sorted and you are told to use back door instead. I feel someone within the organisation should be fighting for the disabled person and we should not have to speak about it and that person should get it sorted. It puts a barrier up for us to not bother asking for things and just put up with it.”*
>
> **Disabled carer with a long-term health condition aged 60-64**

The demand for social care is increasing and access to funding is decreasing[760]. Disability Action recently conducted a small research study on Adult Social Care [761]. 40 respondents, including d/Deaf and disabled people, carers, people who have a family member with a disability or work with deaf and disabled people, completed a questionnaire. The research found that 87% of respondents believed that NI does not have a rights-based approach to independent living. 74% of respondents felt that d/Deaf and disabled people have little or no choice and control in relation to social care in NI.

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[760] British Medical Association (2020): Social care in Northern Ireland.

[761] McDonald, A. (2017): Is Adult Social Care Legislation and Policy Compliant with Article 19 of UNCRPD? Belfast: Disability Action.

Participants in the research informing this report told us of the challenges which they have faced with respect to independent living:

> *"I have had to fight really hard to get even a little bit of support that I need to be able to live independently, I think that this might be due to not "obviously" looking disabled as my support needs are a combination of mental and physical health issues. The only reason why I knew how to fight for some of my needs was due to the employment sector that I am currently working in. Others are not in that position".*
>
> **Woman carer with a long-term health condition aged 16-24**

Prior to the 1970's, people with learning disabilities who could not be cared for at home were placed in institutionalised settings. Three learning disability hospitals remain in Northern Ireland: Muckamore Abbey Hospital (Belfast Trust); Longstone Hospital (Southern Trust); and Lakeview Hospital (Western Trust). In 1995, a decision was taken by the Department of Health, Social Services and Public Safety (the Department) to resettle all long-stay patients from the three learning disability hospitals in Northern Ireland to accommodation offering a better life for the patient[762].

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[762] NIAO (2009): Resettlement of Long-Stay Patients from Learning Disability Hospitals, paragraph 3, p.2.

Despite the resettlement target, many d/Deaf and disabled people within NI remain in institutional and residential settings. Austerity measures, including welfare reform, have been cited as a factor which could lead to increases in the number of d/Deaf and disabled people in institutional and residential settings[763]. d/Deaf and disabled people within institutional and residential settings are isolated and have limited control over life decisions.

Despite resettlement from long stay hospitals being a Government priority since 1995, targets set for resettlement have been breached many times since that date[764]. A renewed commitment to resettle all individuals with a learning disability from hospital by 2013 was not met. A new date for completing the resettlement process by 2015 was set and, once again, missed[765].

Work to complete the resettlement of the patients remaining in Muckamore Abbey Hospital is ongoing, although in common with other HSC activity, the pace of the resettlement programme has been impacted by the Covid-19 pandemic.

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[763] Centre for Welfare Reform (2017): Back to Bedlam What Kind of Future Faces People with A Learning Disability? (accessed 5 November 2021).

[764] NIHE (2014): The Hospital Resettlement Programme in NI after the Bamford Review (accessed 10 October 2021).

[765] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, para 2.13.3, p.25.

As of 5 February 2021, there were 44 inpatients in MAH, with a further 2 patients on trial resettlement. One patient was on extended home leave at the request of their family. Of the patients on site at this date, one was undergoing active treatment, and the remaining 43 have had their discharge delayed[766].

Allegations of abuse at Muckamore Abbey in 2017 stimulated public outcry and have resulted in criminal investigations[767] and a public inquiry[768].

People with a learning disability continue to remain in hospital, even though they no longer need treatment and could be resettled into the community[769]. Funding has not matched the levels identified as being needed in the Bamford Review of Mental Health and Learning Disability to support resettlement[770].

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[766] AQW 16257/17-22

[767] Seanín Graham, (2018): Police probing more than 70 allegations of 'ill treatment' at Muckamore hospital, Irish News, 15 August 2018 (accessed 20 October 2020).

[768] Department of Health (2020): Swann announces Public Inquiry into Muckamore Abbey Hospital (accessed 20 October 2021).

[769] NIHE (2014): The Hospital Resettlement Programme in NI after the Bamford Review (accessed 10 October 2021).

[770] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.13.3, p.25.

Concern has also been expressed about d/Deaf and disabled people staying long term (2 years+) in assessment and treatment units. Although these units are meant to be for short term placements, for a number of reasons there have been delays in discharging people into the community[771].

Participants in the qualitative research informing this report told us of the challenges they experienced in accessing appropriate care packages resulting in some participants having to remain in hospital in the absence of an appropriate care package:

> "*People with complex care needs (or even just needed two carers to call up to four times a day) are being forced to remain in hospital against their will due to not having a care package in place. They are then told by healthcare workers that they are bed blocking and threatened with being discharged into a nursing home. This is bullying. It prevents people with disability from living independently in NI. Furthermore, many OTs in the community do not have the knowledge, funds etc to ensure that their clients receive the correct appliances at home to enable them to live independently.*

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[771] Ibid.

> *There are only very limited amounts of equipment available for the person to be rehabilitated/reenabled at home. This can be blocked further by Occupational Therapists, Doctors etc., pre-discharge*".
>
> **Disabled person with a long-term health condition**

d/Deaf and disabled people, and elderly people in institutional settings are particularly vulnerable to COVID 19. It has been estimated that between 30 – 60% of all COVID-19 deaths across Europe have been d/Deaf and disabled people placed in long term care facilities[772].

Welfare reform continues to negatively impact upon access to independent living opportunities particularly with respect to reductions in income and the disproportionate impact of welfare reform on d/Deaf and disabled people[773]. Furthermore, challenges in accessing affordable transport (in both urban and rural settings) reduces access to independent living by d/Deaf and disabled people. Accessibility is a pre-condition for independent living[774].

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[772] ECDC Public Health Emergency Team (2020): High impact of COVID-19 in long-term care facilities, suggestion for monitoring in the EU/EEA, May 2020, European Surveillance 25(22), 4 June 2020 (accessed 20 October 2021).

[773] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.37 (accessed 10 October 2021).

[774] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.37 (accessed 10 October 2021).

In 2015 the original UK wide Independent Living Fund (ILF) closed completely, and after public consultation, the NI Executive announced that recipients from NI who previously received funding from the ILF UK would continue to receive funds administered, on behalf of the Executive, through ILF Scotland (ILFS), established the same year. However, since 2010 the Northern Ireland Independent Living Fund has been restricted to existing users. The number of recipients decreases each year due to ageing, and declining health conditions requiring nursing based residential settings and mortality. Existing recipients must also contribute part of their Personal Independence Payment (PIP) award towards the cost of personal assistance alongside the ILF award.

In April 2019, the ILF NI and Scotland Stakeholder Groups came together for the first time. Recipients highlighted the vital contribution the Fund makes to their lives and together with non-recipients of ILFS raised the prospect of the fund reopening to new applicants.

As a result, ILFS and the Centre for Independent Living Northern Ireland completed an impact evaluation which found that for those who received the Fund, it fulfilled the Government's obligations under Article 19[775], and, as such, is a prime example of best practice.

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[775] O'Neill, E. and Fitzpatrick, F. (2020): Independent Living Fund Northern Ireland Impact Evaluation, Foreword (accessed 5 Nov 2021).

The Department of Health has established an Independent Living Fund Working Group to develop options for the opening up of the Fund to new applicants.

Participants in the qualitative research informing this report, placed importance on the need for local decision makers to act to advance the right of d/Deaf and disabled people to live independently:

> "*Attitudes of decision makers need to change - it is not a favour or some sort of nice deed- it's a fundamental right to be able to live your life as an independent human being and experience life in a fulfilled and dignified manner".*
>
> **Disabled woman, carer, and DPO representative, aged 40-44**

In its consultation on 'Power to people: Proposals to reboot adult social care and support in Northern Ireland', the Department of Health noted that while there was support for the concept of Self-Directed Support[776], progress had been slow[777].

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[776] The aim of Self Directed Support is to enable individuals to choose how their support is provided and to provide control over personal budgets. An individual's personal budget can be taken as a Direct Payment; or alternatively as a Managed Budget (where the Trust holds the budget, but the individual is in control of how it is spent). The Trust can arrange a service, or the individual can choose a mix of these options. 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.

[777] Department of Health (2016): Power to the People (accessed 5 November 2021).

Several key issues were identified by consultees including the level of personal budget; limited brokerage support; and perceived administrative burden. Stakeholders however believe that if these challenges could be addressed, models of self-directed support could play a key role in promoting independence, ensuring that the focus of support is on ‘a life not a care package’[778].

There is an absence of information regarding the extent to which the needs of d/Deaf and disabled people with substantive needs and who are not in receipt of the Independent Living Fund payments are met by Self-Directed Support (SDS) and Direct Payment Provisions[779]. Direct Payments do not fund many of the activities funded by the Independent Living Fund as the emphasis is upon addressing social care needs rather than promoting independence meaning that those in receipt have access to less support and have less control[780].

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[778] Department of Health (2016): Power to the People Full Report, p.26 (accessed 5 November 2021).

[779] UKIM (2018): Progress on disability rights in the United Kingdom, p.12 (accessed 10 October 2021).

[780] IMNI (2017): United Nations Convention on the Rights of Persons with Disabilities Jurisdictional ‘Parallel’ Report on Implementation in Northern Ireland: Working Paper, p.42 (accessed 2 November 2021).

Legislation underpinning social care delivery across the four UK nations has operated under the frame of austerity since 2010[781]. Direct payments emerged as a consequence of the grassroots activism of local groups of d/Deaf and disabled people and featured in care systems across the UK[782].

The potential direct payments to promote Independent Living has been hampered by cost savings to social care budgets[783]. The drive to adopt personalisation in Northern Ireland emanated from the Transforming Your Care (TYC) programme which proposed broad support for increased individual control over budgets across health and social care reform[784].

In June 2015, phased implementation of Self-Directed Support (SDS) commenced across the five health and social care trusts[785]in Northern Ireland. SDS is promoted as a means through which individuals can gain greater control over how their own social care needs are met[786].

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

[782] Ibid.

[783] Pearson, C. and Ridley, J. (2016): Is personalisation the right plan at the wrong time? Re-thinking cash-for-care in an age of austerity, Social Policy and Administration, 51 (7). pp. 1042- 1059.

[784] DoH (2011): Transforming Your Care (accessed 10 October 2021).

[785] Patient and Client Council (2019): Our experiences of self-directed support, p.4 (accessed 10 October 2021).

[786] Duffy, S. (2018): Self-Directed Support, If It's So Good Then Why Is It So Hard?,

SDS has the intention of supporting Independent Living, providing flexibility and choice that enables deaf and disabled people to access alternatives to institutionalisation. Those who access SDS are allocated a personal budget by their local health and social care trust to support their assessed need for social care.

As highlighted above, concerns about the level of budget, limited brokerage support[787] and the administrative burden associated with SDS are attributed to low uptake of the scheme[788]. Numbers in receipt of SDS are rising incrementally but remain low. See table 1.

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[787] Brokerage is one aspect of an independent support approach which has the aim of providing impartial information, advice and support for people to help them plan and organise their own support arrangements, and make maximum use of community resources and informal support, helping people find creative solutions to meet their needs. This aspect of SDS is not adequately accessible or funded sufficiently to have the required impact within the region.

[788] DoH (2016): Power to the People Full Report, p.97 (accessed 5 November 2021).

Table 1: Number of Direct Payments made by Quarter from 30th June 2020 to 30 June 2021[789]

HSC Trust	Quarter ending				
	30-06-2020	**30-09-2020**	**31.12.21**	**31.03.2022**	**30.06.22**
Belfast HSC Trust	914	901	933	911	939
Northern HSC Trust	898	911	935	948	951
South Eastern HSC Trust	1,130	1,339	1,478	1,447	1,526
Southern HSC Trust	959	959	959	959	959
Western HSC Trust	1,456	1,663	1,809	1,801	1,812
Total	**5,357**	**5,773**	**6,114**	**6,066**	**6,187**

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[789] DoH (2021): Quarterly direct payment statistics June 2021.

In 2016, a new model of health and social care was set out in the Bengoa Report[790] as part of a 10-year strategy to transform the healthcare system. The report is strongly centred on health provision, acknowledging the role of social care mainly through its impact on hospital admissions[791]. Progress in the development and implementation of health and social care policies in Northern Ireland has been slow, with the suspension of the devolved government (2017–2020) and the ongoing Covid-19 crisis delaying progress.

Adult Social Care services are continuing to undergo reform with an emphasis upon prevention, more support for making individual's homes the centre of care where possible, centralisation of specialist services, and better cooperation (and efficiency) between different sites and services. Covid-19 and budget pressures continue to place pressure on services and limit the impact of reform[792].

Participants in the qualitative research underpinning this study told us of the need to invest in and value social care to enable d/Deaf and disabled people to live independently:

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[790] DoH (2016): Systems, Not Structures - Changing Health and Social Care - Full Report (accessed 16 December 2021).

[791] Birrell, D. (2016): The Contribution of the Bengoa Report to Health and Social Care, Public Affairs (accessed 5 November 2021).

[792] Scope (3 March 2021): Where next for health reform? (NICVA) (accessed 5 November 2021).u

> “*Social care workers should be properly trained and rewarded for the work they do. Until social care is valued and respected as a profession, and rewarded accordingly, it will be difficult to attract and retain sufficient people of the right quality to ensure that disabled people have the right support at the right times to enable them to live the lives they choose.”*
>
> **Non-disabled woman and care, aged 60-64.**

While the Disability Discrimination Act 1995 is designed to protect all those with the protected characteristics, it does not ensure independent living as a right.

Participants in the research informing this report told us how Covid-19 had increased financial pressures and reduced opportunities for independent living:

> “*At the moment everything is squeezed financially and COVID has added to the pressures on health and social care budgets. This means that the opportunity for independent living will also be squeezed with less support and accommodation available. At present I think the system is not working and needs re-assessed and action taken to implement plans to support people to live independent lives.*

> *This is not just a health and social care issue and shouldn't be confined as such - it spans across all society - independent living also includes infrastructure, access to buildings, access to employment, access to education, access to housing, social attitudes and, provision of support in all these things - more joined up thinking needed”.*
>
> **Disabled woman carer with long-term health condition**

Right to Independent Living Case Study

Following a change in their needs, a person with disabilities, who hitherto been living at home with a small home care support package, was told by a Health Trust that they would have to move to nursing home care. The individual was not given any other choice but were simply told that this was their only option “that could meet their needs’” and that “the budget for providing a home care package was not available”. No thought had been given to this person’s rights to live independently or to the impact that moving to nursing home care would have on the individual’s ability be an active member of their community. The only consideration was to meet the individual’s ‘assessed need’ so that their basic needs were being met.

This is not an isolated case. Disability Action is aware that the practice of being told that ‘no money’ is available for a care package has impacted on many people resulting in denial of choice and control over their lives. Furthermore, there is a ‘knock on’ effect. The nursing care facility they are in are not able to offer their space to another person leading to longer waiting times. This means the choices and control available to other d/Deaf and disabled people are also denied[793].

The Disability Strategy Expert Advisory Panel report[794] made the following recommendations to be actioned by the forthcoming Disability Strategy specific to Article 19:

- 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” – specifically the human rights approach proposed in reform of adult social care;

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[793] Disability Action Case Load 2020.

[794] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.37 (accessed 10 October 2021).

- new build of Lifetime Homes incorporating 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;
- 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[795].

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[795] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, pp. 37-38 (accessed 10 October 2021).

Article 20: Personal mobility

Article 20[796] requires the Executive to do everything possible to ensure d/Deaf and disabled people can get around as independently as possible, including by: ensuring people can travel when they want at a price they can afford, ensuring people have access to quality, affordable mobility aids, including new technology, or help from other people, to assist them get around, and providing mobility training to d/Deaf and disabled people and staff working with them encouraging manufacturers of mobility aids and technologies to think about all aspects of mobility for disabled persons.

Article 20[797] provides a non-exhaustive list of the type of measures to be taken:

> (a) facilitating the personal mobility of persons with d/Deaf and disabled people in the manner and at the time of their choice and at affordable cost;
>
> (b) facilitating access by d/Deaf and disabled to quality mobility aids, devices, assistive technologies, and forms of live assistance and intermediaries, including by making them available at affordable cost;

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[796] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 25.

[797] Ibid.

(c) providing training in mobility skills to d/Deaf and disabled people and to specialist staff working with de/Deaf and disabled people;

(d) encouraging organisations that produce mobility aids, devices, and assistive technologies to take into account all aspects of mobility for persons with disabilities.

State parties are obliged to provide adequate funding and financial support. Policies or strategies related to mobility devices require resources and should form a core aspect of budget negotiations.

Article 20[798] focuses on the necessity to facilitate access to appropriate instruments and technology, or to promote their development with the aim of encouraging and supporting the capacity of persons with disabilities to freely move and to respect, consequently their right to inclusion in the society.

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[798] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 25 (accessed 4 November 2021).

Personal mobility is also dependent upon the right to health (Article 25[799]); to the right to habilitation and rehabilitation (Article 26[800]); to the right to work and employment (Article 27[801]); to the right to education (Article 24[802]); and to the right to participation to cultural life, recreation, leisure, and sport (Article 30[803]). In effect, the realisation of all these rights depends on, and is conditioned by, the possibility for d/Deaf and disabled people to move autonomously. It is not just physical barriers which people with disabilities encounter in personal mobility; for people with a learning disability, in particular, there are psychological barriers. Initiatives such as independent travel training are available, but availability is sporadic[804].

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[799] Ibid, Article 25.

[800] Ibid, Article 26.

[801] Ibid, Article 27.

[802] Ibid, Article 24.

[803] Ibid, Article 30.

[804] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.14.2, p.26.

Assistive Technology (AT) can refer to any product or service that can be used by d/Deaf and disabled people to overcome challenges they may face in carrying out daily activities of their choice that would otherwise be limited. AT covers services and the environment in which they operate and includes both "mainstream" technologies and those developed specifically for d/Deaf and disabled people[805].

Access to assistive technology can be costly for people with disability. Although schemes such as Access to Work can help for people in work, there is no similar scheme for people who are not working or who can only use their equipment in work or school. Health Trusts may make funding available for communication aids but are less likely to fund computer equipment. Very often d/Deaf and disabled people are therefore left to rely on charity to try and raise funds for vital equipment[806].

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[805] Cook, A.M. and Polgar, J.M. (2020): Assistive technologies: principles and practice

[806] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.14.2, p.26.

Mobility devices may be provided by a broad range of stakeholders such as governments, international agencies, non-governmental organisations, and the private sector. Mobility devices may be accessed by d/Deaf and disabled people through a number of different facilities, including hospitals, rehabilitation facilities, mobile/outreach facilities, community-based programs, private retailers and special education agencies. A variety of health personnel, especially rehabilitation personnel, is involved in the provision of mobility devices, including therapists (e.g. occupational therapists and physiotherapists), medical staff (e.g. doctors and community-based rehabilitation workers and community health workers). The provision of mobility devices is generally a low area of priority for the Northern Ireland Executive[807].

Aids and Equipment are generally supplied by the HSCT and there are a range of regional and local services, for example, the regional wheelchair service. However, some d/Deaf and disabled people have experienced long waiting times for the appropriate aid or equipment. For example, waiting nearly one year for an appropriate shower chair to be provided[808].

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[807] Ibid.

[808] Ibid, pp. 26-27.

d/Deaf and disabled people have told us about the difficulties they experience in using the current technology used for the driving theory test[809]. It does not allow for reasonable adjustments for disabled people[810].

The loss of Motability as a result of PIP is having a significant impact upon personal mobility[811].

The authors of this report propose the following recommendations:

- ensure that d/Deaf and disabled people have access to aid, equipment, and technology that this is suitable for their needs in a timely manner;
- ensure access to appropriate training and support to promote independent travel for people with learning disabilities;
- ensure access to reasonable adjustments within the driving theory test.

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[809] Nothing About Us Without Us: The Rights of d/Deaf and Disabled People, 24 November 2021; The Rights of d/Deaf and Disabled Women 9 December 2021; Disability Action Case Load 2021.

[810] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.14.3, p.27.

[811] Ibid, 2.14.4, p.27.

Article 21: Freedom of Expression and Opinion, and Access to Information

> "*There are barriers to living independently such as a lack of information being available or provided, a lack of outreach to disabled people, misallocation of funds, and more".*
>
> **Disabled man aged 16-24**

Article 21[812] requires State parties to take all appropriate measures to ensure that d/Deaf and disabled people can exercise freedom of expression and opinion. This includes the freedom to seek, receive and impart information and ideas on an equal basis with others and through communications of choice. Article 21[813] requires:

- the provision information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

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[812] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 21 (accessed 4 November 2021).

[813] Ibid.

- facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes, and formats of communication of their choice by persons with disabilities in official interactions;
- urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- recognising and promoting the use of sign languages.

The UN Committee raised the following concerns regarding the limited provision of accessible information from public services and public authorities and the insufficient obligatory standards for making websites accessible and for monitoring ICT accessibility:

- insufficient resources for the education and training of sign language interpreters and the insufficient availability of high quality educated sign language interpreters, especially in relation to education, employment, health, and leisure;

- the lack of training and education for families, classmates, and co-workers in high quality sign language communication in order to better provide for inclusion within the community of d/Deaf and hard of hearing persons.

The Committee recommended that the NI Executive in consultation with DPOs:

- identify outstanding gaps in the implementation of obligatory accessibility standards on information channels based on ICT;
- ensure that legislation provides for the right to high quality sign language interpretation and other forms of alternative communication in all spheres of life for d/Deaf and disabled people and hard of hearing persons in line with the Convention;
- allocate resources for the education of children with hearing impairments, their families, and others, such as classmates and -workers in sign language and tactile language[814].

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[814] 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, CRPD/C/GBR/CO/1, paragraphs 44 and 55 (accessed 20 December 2021).

Accessible communication continues to be a barrier to d/Deaf and disabled people in NI accessing their right to freedom of expression and opinion. There are no accessible communication standards in NI. While some public agencies have guidelines in place, they are not mandatory and are rarely monitored[815].

Alternative formats are currently being produced by a very limited number of groups. This is a negative situation as it creates a backlog in processing requests for information to be produced in the required alternative format. Therefore, there should be an increase in the number of providers who are authorised to undertake this vital work. Accessible communication is a significant barrier to health and social care and has an impact on Article 22 and the right to privacy[816].

The requirement of public authorities to supply communication support is outlined in the Disability Discrimination Act 1995. In 2017, DWP reviewed the UK market for communication service provision for people who are d/Deaf and hard of hearing, key findings included:

- the demand for communication services is high and growing due to equality and disability measures;

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[815] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.15.1, p.28.

[816] Ibid.

- unmet demand and inappropriate communication support for d/Deaf people are common in employment, public services (health, justice), higher education and primary education[817];
- Government has no provision to measure the volume of demand or scale of unmet demand;
- There is an insufficient pool of professionals working in the communication support sector, leading to an inappropriate use of lower qualified communication support workers[818];
- new technology is broadly welcomed by the d/Deaf community. In certain situations, technology cannot replace one to one interpreting support (e.g., medical settings, long business meetings)[819].

Many British Sign Language (BSL) users see themselves as a cultural and linguistic minority community rather than a disability group[820]. In NI there are two recognised sign languages, Irish Sign Language (ISL) and British Sign Language (BSL). BSL and ISL are distinct languages, not dependent upon, nor strongly related to spoken English and Irish.

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[817] DWP (2017): Market Review BSL and Communication Provision, p.9 (accessed 20 December 2021).

[818] Ibid p.9 and p.30.

[819] Ibid, p.8.

[820] British Deaf Association (2014): Legal Status of BSL – ISL (accessed 20 December 2021).

There is no universal sign language[821]. There is no agreed estimate of the number of people within the d/Deaf community in Northern Ireland. Some figures estimate that approximately 18,000 BSL and ISL users live in Northern Ireland, 7,500 of whom are d/Deaf.

The Health and Social Care Board reported difficulties in capturing the numbers of full-time equivalent interpreters and the levels of unmet need for interpretation support in NI[822]. The COVID-19 pandemic has highlighted the necessity of adequate ISL and BSL services particularly for public health messaging as well as digital communication services. DfC launched a £430,000 Sign Language COVID-19 Support Fund in November 2020[823].

The official recognition of BSL and ISL by the Northern Ireland Secretary of State in 2004 did not provide any statutory protection or legal status[824]. d/Deaf people in NI currently rely on the provisions of the Disability Discrimination Act 1995 to access 'reasonable adjustments' such as interpreter provision. This means that BSL/ISL users must identify as 'disabled' to access essential public services. As previously outlined, deafness as a disability is a medical perspective, whereas

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[821] RAISE (2020): Sign Language Legislation, p.1 (accessed 20 December 2021).
[822] Ibid.
[823] Ibid.
[824] RAISE (2020): Sign Language Legislation, p.21 (accessed 20 December 2021).

many in the d/Deaf community view themselves as a cultural and linguistic minority[825]. In addition:

- a higher proportion of d/Deaf young adults are not in education, employment, or training[826];
- d/Deaf people experience a poorer quality of health[827];
- d/Deaf women are twice as likely as hearing women to experience domestic violence due to difficulties accessing specialist support systems[828].

DfC had a Sign Language Partnership Group, sometimes referred to as the ‘Hands-on Partnership’. This group included representatives from each of the NI Departments as well as deaf community organisations. This group supported the development of the Sign Language Framework and proposals for sign language legislation[829]. The Assembly have introduced a pilot which provides live signing at the Executive Office at Question Time[830].

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[825] Ibid, p.22.

[826] DfC (2016): Sign Language Framework, paragraph 3.52, p.34 (accessed 20 December 2021).

[827] BMJ (2014): The Current Health of the UK Deaf Community (accessed 20 December 2021).

[828] Women’s Aid (2015): Deaf survivors and domestic abuse (accessed 20 December 2021).

[829] NI Assembly (2014): Official Report: Minutes of Evidence (accessed 20 December 2020).

[830] NI Assembly (2021): NI Assembly to introduce live sign language for Executive Office Question Time (accessed 31 December 2021).

The process was first trialled at the Disabled Person's Parliament on 3 December 2021[831]. Michelle O'Neill, Deputy First Minister became the first Minister to uses sign language in the Chamber[832].

The Disability Strategy Expert Advisory Panel have made the following recommendations:

- 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;
- the provision of GCSE sign language.

The Authors of this report also recommend that the Executive ensure that there is adequate provision of BSL and ISL interpreters in NI**.**

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[831] NI Assembly (2021): Disabled People's Parliament (accessed 31 December 2021).

[832] BBC News (13 December 2021): As it happened: Assembly Debate Covid-19 passports: Five points you need to know from Executive Office Question Time (accessed 31 December 2021).

Article 22: Respect for privacy

Article 22[833] of the UNCRPD protects personal and family privacy and reputation. Article 22[834] requires that no disabled person, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home, correspondence or other types of communication, or to unlawful attacks on his or her honour and reputation. Article 22[835] requires that Persons with disabilities have the right to the protection of the law against such interference or attacks. State parties are required to protect the privacy of personal, health and rehabilitation information of disabled people on an equal basis with others.

International Human Rights Law protections for privacy are generally thought to include privacy of personal information, privacy of communications, privacy of personal environment, such as one's dwelling and other personal spaces, and freedom from attacks on personal reputation. Privacy is a value, and its protection furthers other values that human beings cherish[836].

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[833] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 22.

[834] Ibid.

[835] Ibid.

[836] Wachter, S. (2017): Privacy: Primus Inter Pares: Privacy as a Precondition for Self-Development, Personal Fulfilment and the Free Enjoyment of Fundamental Human Rights (accessed 20 December 2021).

Lack of accessible communication in health and social care, as highlighted in the commentary with respect to Article 21, continues to impact on the right to privacy of people with disabilities. All too often people with disabilities rely on families or friends to help them access health and social care information. This means that they do not have the same level of privacy as their non-disabled peers[837].

Disability Action are aware of a case in which a person requested that their information be sent to them by email so that they could access it, and have it read aloud as they could not access printed information. The Health Trust stated that they could not do this due to Data Protection Legislation.

The fact that giving the information in printed format would have meant the person having to get someone else to read the information, and therefore remove the privacy, was completely overlooked.[838] This is particularly concerning during the pandemic when healthcare is being delivered remotely. This issue was raised during the Disabled Person's Parliament on 3rd December 2021[839].

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[837] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.1-2.16, p.29.

[838] Ibid.

[839] NI Assembly (2021): Disabled Person's Parliament, 6 December 2021 (accessed 21 December 2021).

Article 23: Respect for privacy and family

Article 23[840] requires State parties to take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, on an equal basis with others. This includes ensuring that:

a) the right of all d/Deaf and disabled people who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognised;

b) the rights of d/Deaf and disabled people to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;

c) d/Deaf and disabled people, including children, retain their fertility on an equal basis with others.

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[840] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 22 (accessed 4 November 2021).

State parties are required to:

- ensure that the rights and responsibilities of d/Deaf and disabled people, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount;
- render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities;
- ensure that children with disabilities have equal rights with respect to family life;
- prevent concealment, abandonment, neglect, and segregation of children with disabilities;
- undertake to provide early and comprehensive information, services, and support to children with disabilities and their families;
- ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both parents;

- to act in instances where immediate family is unable to care for a child with disabilities, to undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.

The UNCRPD Committee is concerned that d/Deaf and disabled parents do not receive appropriate services and support, resulting in children being removed from the family environment and placed in foster care, group homes or institutions. The Committee was also concerned about insufficient funding for parents of d/Deaf children to learn sign language.

The Committee recommended that the State party ensure:

- appropriate support for d/Deaf and disabled parents to effectively fulfil their role as parents and ensure that disability is not used as a reason to place their children in care or remove them from the family home;
- local authorities have the legal duty to allocate funds for parents wishing to learn sign language[841].

There is also a requirement for States to support the family structure.

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[841] 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, CRPD/C/GBR/CO/1, paragraphs 48 and 49 (accessed 20 December 2021).

As noted under Articles 15, 16 d/Deaf and disabled are at risk of being institutionalised which limits their capacity to enjoy respect for privacy and family life. Key concerns associated with Article 23 are also addressed in Article 6 and Article 7.

There are limited support services for families and an absence/lack of community-based services for children with disabilities, particularly those children with complex needs 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 d/Deaf and disabled children and their siblings[842].

Participants in the qualitative research informing this report told us about their experiences as parents of disabled children who had limited choices and when they became sick had limited options other than supported living for their children:

> “*When parents are elderly and sick themselves, the choices they have is no choice. Living in supported living, not toileted, showered, cuts and bruises, medical care ignored, this was a trust run facility. Complaints ignored. No help from anyone.”*
>
> **Disabled carer with a long-term health condition**

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[842] Mencap (2006): Breaking point: families still need a break.

Health and Social Services provision collapsed during the pandemic. In 2020, 70% of people living in supported accommodation or residential care were not allowed by service providers to have visitors into their home. This was also the case for 20% of people living with families or in their own accommodation.

By August 2021, around 5% of persons with a milder learning disability still had restrictions placed upon them but these restrictions rose to 25% of those with more severe disabilities. Two-thirds of persons with severe or profound learning disabilities were reported by carers to have reacted negatively to visitor restrictions: isolation, boredom, frustration, and confusion about why things had changed[843].

Families of people with learning disabilities have described the collapse of support services as having devastating impacts on their lives and the lives of people with learning disabilities. The majority of services have not been re-established with only 5% of almost 200 people with learning disabilities and their families reporting that their lives have returned to normal[844].

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[843] Taggart, L., McConkey, R. and Mulhall, P. (2021): The impact of COVID-19 on people with learning disabilities in Northern Ireland: Implications for policy and practice, paragraph 3.4 (accessed 21 December 2021).

[844] Ibid.

Right to Privacy and Family Life Case Study

Peggy and Seamus McKenna have reported that they have had only very limited visits with their daughter Orla, who resides in Abingdon Manor Care Home, for 20 months. Peggy and Seamus are concerned that their daughter will not understand why they are absent. They also reported that Orla previously attended a day centre 5 times a week and visited her home every weekend. Orla has not left Abingdon Manor since March 2020[845].

Informal (unpaid) family carers are an integral part of all societies and the health and social care systems in the UK depend on them[846]. Despite the valuable contributions and key worker status of informal carers, their lived experiences, wellbeing, and needs have been neglected during the COVID-19 pandemic[847]. Research by Carers NI demonstrated that £4.8bn of care during the pandemic was undertaken by families in NI[848]. Carers NI have recommended that carers allowance should be increased by £20 per week[849].

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[845] BBC (2021) Coronavirus: Who can do this to our daughter?.

[846] Onwumere, J., Creswell, C., Livingston, G. et al. (2021): COVID-19 and UK family carers: policy implications, Lancet Psychiatry, 2021;8(10):929-936.

[847] Ibid.

[848] Carers NI (2017): Unpaid carers save state £19 million every day of pandemic.

[849] Ibid.

Carers in NI have expressed concern that their issues are not being addressed, including the impact on their own physical and mental health; detriment to their own life outside of caring; difficulties in balancing caring with paid work often leading to financial difficulties (compounded by cutbacks in social provision and increases in direct costs); and for young carers – impact on development of social skills, family relationships, and education/career prospects[850].

In response to concerns raised regarding the experience of carers during the pandemic, Health Minister Robin Swann announced a £4.4mn Support for Carers grant scheme for community and voluntary organisations in April 2021[851]. The grant scheme was administered and managed by Community Foundation NI and was open to community and voluntary sector organisations with charitable purposes offering support to carers and operating within Northern Ireland. The allocation was funded through one off emergency funding made available to the Department of Health.

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[850] Ibid.

[851] DoH (2021): Unpaid carers are the backbone of society - Swann (accessed 21 December 2021).

The Support for Carers Fund was intended to achieve the following outcomes:

- enhanced provision of and access to practical supports and help for carers;
- improved access to and availability of advice services for carers, including support available through new technologies;
- enhanced skills of carers to advocate for the needs of both themselves and the person they care for;
- support for improved physical and mental health and wellbeing of carers;
- enhanced ability for carers to lead their own lives and enjoy a work/life balance;
- increased capacity to advocate for and advance carers' issues with Government and statutory bodies;
- raised awareness of the contribution of carers;
- improved evidence base on carers to support and inform service provision, and Government strategy[852].

This fund, while welcome, did not address levels of poverty and disadvantage experienced by unpaid carers.

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[852] Ibid.

The most recent specific legislation in NI was the Carers and Direct Payments Act (Northern Ireland) 2002, which gave carers the right to an assessment and to be considered for services to meet their assessed needs. It placed a duty on Health and Social Care Trusts to inform carers of their right to a care assessment and the right to provide personal social services to support carers directly. However, Trusts retain discretion to decide whether to provide service(s) to meet a carer's identified needs[853].

NI is lagging behind the rest of the UK in addressing carers' issues, in terms of both strategy and legislative development[854]. Caring for Carers (2006) is the most recent NI strategy, whereas more recent strategies have been published in Scotland in 2010, in Wales in 2013, and in England in 2014[855].

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[853] NI Assembly (2018): Supporting carers in Northern Ireland: Where are we with legislation and policy? (accessed 21 December 2021).

[854] Ibid.

[855] The Care Act 2014 and Children and Families Act 2014 in England; The Carers (Scotland) Act 2016; and The Social Services and Well-being (Wales) Act 2014 (accessed 27 March 2022).

Talking to d/Deaf and disabled people has highlighted the difficulty for parents with a disability accessing the appropriate support to raise their family[856]. In a number of cases, rather than offering the appropriate supports, the first reaction has been to remove the child from the parent. There are also cases where social services have been present, purely on the basis of a parent having a disability. Unfortunately, a lack of disaggregated data does not allow for the development of a sound evidence base[857].

The process of the reform of adult social care is currently being taken forward by the Department of Health[858]. The 'Power to the People' report proposes to put the rights of family carers on a legal footing and recommends that a Strategy is required to place carers at the heart of the transformation of adult care[859].

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[856] Nothing About Us Without Us, 24 November 2021.

[857] Nothing About Us Without Us, 24 November 2021.

[858] DoH (ND): Reform of Adult Care and Support, (accessed 21 December 2021).

[859] DoH (2017): Power to the people, p.39 (accessed 21 December 2021).

There is a lack of information for young people and families about the options available, as well as difficulties in identifying the right level and range of services and support for young people to 'transition' into. The funding and sustainability of alternatives to statutory provision, which is often short term in nature, increases the worry and anxiety of families and the young people concerned and affects their ability to plan for their own future and to be in control of their own life.

The potential complexity caused by the fact that children and young people with disabilities may have to navigate dual transitions from school to further education, training, or employment and from child to adult health and social care services was articulated in the 'Review of Transitions to Adult Services for Young People with Learning Disabilities' (Northern Ireland Commissioner for Children and Young People: 2012) which highlighted the need for integrated planning[860]. Young people who have significant health and social care needs will experience a transition from child to adult services. Transition to adult social services usually takes place at eighteen, although the age at which young people are no longer eligible for a service may vary from service to service[861].

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[860] Lundy, L., Byrne, B. and McKeown, P. (2012): Review of transitions to adult services for young people with learning disabilities, p.5 (NICCY) (accessed 1 January 2022).

[861] NICE (2016): Transition from children's to adults' services for young people using health or social care services, p.4.

There is no agreed standard upper age limit that young people can access children's services before moving into adult services. There is evidence that the transition process is variable, with previous good practice guidance not always being implemented[862]. For example, children may transfer to adult wards in acute hospitals at fourteen; they may transfer from community children's nursing between sixteen and eighteen years; and they may no longer qualify for children's respite services at sixteen years of age[863].

There is a lack of information for young people and families about the options available, as well as difficulties in identifying the right level and range of services and support for young people to "transition" and move into. The funding and sustainability of alternatives to statutory provision, which is often short term in nature, increases the worry and anxiety of families and the young people concerned and affects their ability to plan for their own future and to be in control of their own life[864].

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[862] Lundy, L., Byrne, B. and McKeown, P. (2012): Review of transitions to adult services for young people with learning disabilities, p.20 (NICCY) (accessed 1 January 2022).

[863] Ibid, p.48.

[864] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.17.2, p.31.

Article 23 also provides protections against interference with private and family life, and violations include domestic, violence, sexual assault and rape which have been discussed earlier in the report under Article 6 d/Deaf and disabled women, Article 15 freedom from torture or cruel, inhuman or degrading treatment or punishment[865] and Article 16 Freedom from exploitation and abuse[866]. The Disability Strategy Expert Advisory Panel proposed the following recommendations:

- agree a Short Breaks policy between the Department of Health, health agencies and children with disabilities and their families;
- ensure sufficient and disability-sensitive childcare as a statutory duty[867];
- restore the value of Carers' Allowance to 2010 levels[868].

The authors of this report recommend:

- a review intervention of the transition to adulthood for disabled children and young people.

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[865] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 15. (accessed 4 November 2021).

[866] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106 Article 16 (accessed 4 November 2021).

[867] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.115 (accessed 10 October 2021).

[868] Ibid, p.48.

Article 24: Education

> *"There's a lot of discrimination and negative attitudes within NI especially in social settings plus the primary one is within schools. Disability should be a core aspect of the curriculum; young people should be learning about disability and the need for disability rights. More people would be aware off hidden disabilities, more and more people are being bullied and treated like second class citizens. Knowledge is key for everyone!"*
>
> **Disabled woman carer with long-term health condition, aged 40-44.**

Article 24 of the Convention concerns the obligations associated with access to education[869]. It promotes an inclusive education system with access for all d/Deaf and disabled people at all levels and including lifelong learning. State parties are expected to ensure that:

- d/Deaf and disabled people are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

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[869] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 25 (accessed 4 November 2021).

- d/Deaf and disabled people can access an inclusive, quality, and free primary education and secondary education on an equal basis with others in the communities in which they live;
- reasonable accommodation of the individual's requirements is provided;
- d/Deaf and disabled people receive the support required, within the general education system, to facilitate their effective education;
- effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.

The Convention also requires that State parties take measures to employ teachers who are appropriately trained to work d/Deaf and disabled people, including qualifications in sign language, training in disability awareness and the use of augmentative technologies. In addition:

> '*States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education, and lifelong learning without discrimination and on an equal basis with others*'[870].

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[870] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 24 (accessed 4 November 2021).

A consequence of this is that a State Party is required to ensure reasonable accommodation is provided to a person with disabilities. The UNCRPD Committee raised concerns, in its (2017) concluding observations, regarding the persistence of a dual system of education which segregates children with disabilities in special schools including that which is based upon parental choice. The Committee were concerned regarding the increasing number of children in segregated environments noting the inability of the system to provide high quality inclusive education noting the refusal of schools to enrol students with disabilities for reasons associated with disruption[871].

The Committee recommends the State Party, in close consultation with DPOs, especially those representing children and in line with the Committee's General Comment No. 1 (2014) on the right to inclusive education and targets 4.5 and 4.8 of the Sustainable Development Goals:

- develop a comprehensive and co-ordinated legislative and policy framework for inclusive education which includes a timeframe for mainstream schools to foster the real inclusion of children with disabilities in schools and which ensures that teachers and other

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[871] 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, CRPD/C/GBR/CO/1, paragraphs 52 and 53.

professional understand the concept of inclusion and are able to enhance inclusive education;

- strengthen measures to monitor school practices with respect to the enrolment of children with disabilities and offer appropriate remedies in cases of disability related discrimination and/or harassment including schemes compensation;
- ensure the implementation of laws and regulations to improve both the extent and quality of inclusive education in all settings and across all levels to provide high quality inclusive environments including breaks within lessons and through socialisation outside of class and education time;
- establish awareness raising and support initiatives with respect to inclusive education among parents of children with disabilities;
- provide sufficient data on the number of students both in inclusive and segregated education settings disaggregated by disability, age, gender and ethnic background, and outcome of education[872].

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[872] 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, CRPD/C/GBR/CO/1, paragraphs 52 and 53.

The right to education is a fundamental human right. It is widely acknowledged to be a passport to all other human rights. Respect for the human right to education is essential to enabling the realisation of all other human rights protected within the UNCRPD e.g. the rights of children with disabilities (Article 7), rights to employment (Article 27) and health (Article 25).

d/Deaf and disabled people have the human right to education on an equal basis to people without disabilities. A child who grows up with a disability and who does not meet their educational potential could suffer multiple barriers to personal development and denial of basic life opportunities which others enjoy unhindered. Participants in the qualitative research informing this report told us about their experiences, within school, of feeling excluded and that they needed to be fixed. Many respondents felt that curriculum development and education offered an opportunity for change and to build a better understanding and awareness of disability:

> "*Whilst I think many schools do great in teaching and support disabled students, I think it comes from misinformed ideals around disability. During my school years I experienced a lot of medical model style treatment in school as in I had to be fixed as opposed to being supported and encouraged.*

> *I think NI schools need to include a mandatory disability inclusion class and training. Much of today's problems stem from ignorance, so by teaching kids, both non-disabled and disabled, the true meaning of disability will improve things. Showing them real people and not just tv characters or promoting a medical model cure culture. If kids and staff are exposed to the correct information from actual disabled people, the future generation will hopefully be void of the ableism and distain that has hurt disabled people for so long."*
>
> **Disabled man carer with long-term health, aged16-24.**

Effective implementation of the UNCRPD should mean that all d/Deaf and disabled people enjoy their right to education at all levels free from discrimination and on the basis of equality of opportunity. The UNCRPD requires States Parties to ensure an 'inclusive education system at all levels'[873].

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[873] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 24 (accessed 4 November 2021).

State parties 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 freely 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.

Participants in the qualitative research to inform this report have told us of the barriers which they have faced when in engaging with education and the wider impacts which this can have on independence and accessing opportunities in the future:

> *“I missed about 2 years of school over my time in high school. For 6 months off over 2nd year, I had the hospital school to support me. However, when I was off for medical reasons in my A-levels there is no support outside of regular schooling for those pursuing further education - this makes working towards independence, setting yourself up with a good job and self- actualisation very difficult”.*
>
> **Disabled woman with a long-term health condition, aged 16-24.**

The ‘New Decade, New Approach’ agreement outlines a commitment to ‘deliver a new Special Educational Needs Framework to support young people with special needs to achieve their full potential’[874]. This has not been actioned at the time of writing.

Currently just under 20% of the school population has a reported SEN, equating to 67,224 children in 2019-20, of which 19,200 have a Statement of SEN[875]. In 2019-20, 70 per cent of pupils with a Statement of SEN attended mainstream schools[876].

Legislation pertaining to children with special educational needs is contained within the Education (NI) Order (1996) and The Special Educational Needs and Disability (NI) Order 2005 (SENDO) and is supported by Codes of Practice and statutory regulations. The SENDO (2005) governs protection from disability discrimination in Education and it is linked to the DDA definition of disability. A consultation on new draft SEN regulations and Code of Practice based on the Special Educational Needs and Disability (Northern Ireland) Act 2016 has concluded but the related regulations have yet to be published[877].

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[874] UK Government (2020): New Decade New Approach, p.7.

[875] A Statement of Special Educational Needs (Statement) is a legal document which sets out a child’s educational needs and outlines how the Education Authority (EA) will meet those needs in an educational setting.

[876] Public Accounts Committee (2021): Report on Impact Review of Special Educational Needs, (accessed 4 November 2021).

[877] DE (2021): Consultation on draft SEN Code of Practice.

The 2016 Act requires that a personal learning plan is developed for every child with special needs and gives parents and children new rights to appeal Education Authority (EA) decisions when it does not change a statement to reflect a change in circumstances; and places a new duty on the EA and health and social services to co-operate when identifying, assessing, and providing support to children with SEN.

The EA will be required to publish an annual plan of its arrangements for special educational provision. They will also have to seek and have regard to the views of the child when making decisions on special educational provision. The EA have put in place independent dispute avoidance arrangements and independent mediation arrangements.

Many of these new duties and rights have not yet been introduced as they need to be supported by new SEN Regulations and the new SEN Code of Practice which are currently under development[878].

The 2016 Act places new duties on the Boards of Governors which will include: a requirement to ensure that teachers in the school take all reasonable steps to identify and provide for those children with SEN; the appointment of a Learning Support co-ordinator within each school to coordinate provision for children with SEN; the completion and review of a personal learning plan (PLP) for each pupil with SEN.

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[878] DE (ND): New SEN Framework (accessed 16 December 2021).

Protection from disability discrimination for children and young people in Northern Ireland is significantly out of step with the law in the rest of the UK and the legal protections are weaker. The Equality Act 2010[879] introduced protection against indirect discrimination and 'discrimination arising out of disability in GB. There are no such protections available in NI. This creates a barrier to access to justice in education cases in the region. Furthermore, the remedies available do not reflect the range and severity of the impacts which a child may suffer at school, or when excluded from school because of disability discrimination e.g. financial compensation is not available for disability discrimination by a school[880]. Evidence indicates that children's access to justice often depends on the goodwill of adults and the support they may or may not provide. In many cases, parents, particularly those with lower levels of literacy, are uncertain how to support children to exercise their rights. Furthermore, children often need financial support to meet legal fees[881].

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[879] Equality Act, 2010, Section 19 (accessed 16 December 2021).

[880] See section 22(4) of the Special Needs and Disability (Northern Ireland) Order 2005; In contrast, sections 18-20 and 54 of the Race Relations Order (Northern Ireland) 1997 allow for financial compensation where a child has experienced unlawful racial discrimination in school. See also: IMNI (2017): Jurisdictional 'Parallel' Report on Implementation in Northern Ireland, p.8 (accessed 16 December 2021).

[881] Grandjean, A. (2010): No Rights Without Accountability: promoting access to justice for children, International Development Law Organization, Legal Empowerment Working Paper 10.

Article 16 of SENDO (2005)[882] specifically excludes any obligation under anti-discrimination law for a school to provide a pupil with 'auxiliary aids and services' as part of any 'reasonable adjustments', an anomaly which has been addressed elsewhere in the UK by the provisions of the Equality Act 2010.

The draft SEN regulations do not require the Education Authority (EA) to arrange or fund support or advocacy for young people. The draft SEN regulations detail the process for determining whether a child has the capacity to exercise their rights within the framework[883].

While the recent Mental Capacity Act (2016) requires that all practicable help and support are provided prior to determining incapacity under its provisions, the draft SEN Regulations do not provide for any such support or advocacy. These regulations appear to be in contrast with Article 1 of the SEND Act, which requires the EA to have regard to the importance of a child being informed and supported to enable participation in decision making.

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[882] The Special Educational Needs and Disability (Northern Ireland) Order 2005, article 16 (accessed 2 January 2022).

[883] DE (2021): The draft Special Educational Needs (SEN) Regulations, paragraph 24-27, p.6 (accessed 1 January 2021).

Concerns are routinely reported by a range of stakeholders that children with disabilities are unlawfully excluded from school; placed on reduced timetables; isolated from peers; subjected to bullying; excluded from school trips and activities and punished for minor behaviours which are connected to their disabilities[884].

There is no access to an appeal in Northern Ireland when a child has been formally excluded from school through suspension as the Department has not published regulations to provide for appeal under Article 33 of the Education and Libraries (NI) Order 2006[885].

The Department of Education does not collect data about disability for suspended pupils[886]. Stakeholders report multiple instances of the use of informal exclusion of d/Deaf and disabled children from school in Northern Ireland without being afforded access to due process or legal protection. This is the "norm", rather than the exception in many schools. The Education Authority is aware of and has acknowledged that the facts around SEN appeals raise questions about the validity of the EA's decision-making processes[887].

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[884] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.92 (accessed 10 October 2021).

[885] The Education (Northern Ireland) Order 2006, Article 33.

[886] DE (2021): Pupil Suspensions 2019/20 (accessed 2 January 2022). These statistics report by Level, Gender, school management type, frequency and ethnicity and reason.

[887] NICVA (2021): Disability discrimination against children is "institutionalised" within NI's education system (access 2 November 2021).

The implementation of the SEND Act (NI) 2016 is in progress to enable a new, more responsive, and effective SEN Framework to be put in place. As part of this Framework, new SEN Regulations and the associated Code of Practice are being finalised to provide practical guidance on how the law applies to practitioners. A full training programme is being delivered by the Education Authority.

There is considerable evidence to suggest that the provision of SEN requires significant improvement in light of the reports produced by the Northern Ireland Audit Office (NIAO) in 2017 and 2020[888]. In 2017 NIAO raised concerns regarding escalating costs associated with SEN provision in the absence of an evaluation of support to identify measures which are most likely to stimulate the best outcomes[889]. The report highlighted inconsistencies in the identification of children with SEN and unacceptable delays in the statementing process[890]. The report outlined 10 recommendations which include:

- the Department of Education (DE) and the EA should ensure that schools apply a clear and consistent approach to identifying, and providing for, children with SEN;

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[888] NIAO (2020): Impact Review of Special Educational Needs (accessed 30 October 2021).

[889] NIAO (2017): Special Educational Needs p.3 (accessed 8 December 2021).

[890] Ibid, p.3.

- DE, the EA, and schools should ensure that all teachers, including those studying for their teaching qualification, receive appropriate training so they are able to identify children with SEN and take the necessary action to provide support to them;
- the EA must record and monitor the reasons for all delays in issuing statements to take effective action to reduce waiting times;
- DE should continue to work to improve the waiting time for Statutory Assessments. This should include co-ordinating with the Department of Health to agree on an improved achievable timescale for receiving advice;
- the EA must ensure that SEN expenditure is reported consistently and that EA expenditure on all types of support for children with SEN can be easily identified and monitored, otherwise it cannot be controlled;
- DE and the EA should review the current funding arrangements to ensure that available resources are used effectively to meet the needs of all children with SEN, with or without a statement;
- DE should give further consideration to the level of expertise within each inspection team, to ensure that SEN provision is evaluated in mainstream schools by a specialist, particularly where there are a high proportion of children with SEN;

- the Department should commission the ETI to carry out an up-to-date evaluation of SEN provision in mainstream schools which could play a key part in highlighting areas to be addressed in the development of SEN strategy and future training programmes. A particular focus in primary schools should be the use of, and effectiveness of, early intervention strategies;
- DE and the EA must assess the quality of SEN support provided in mainstream schools by formally evaluating it in terms of the progress made by children. This will allow resources to be focused on types of support which maximise progress and improve outcomes;
- DE and the EA should set up a central resource containing all up-to-date guidance relating to SEN which could also act as a discussion forum for sharing ideas and good practice examples[891].

In 2020 the NIAO published an Impact Review of Special Educational Needs[892] which called for an urgent review of SEN to target resources at the best possible outcomes, noting that although it was 13 years since the Department of Education had commenced a review of SEN at a cost of £3.6m, this still remained incomplete[893].

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[891] Ibid, p.5.

[892] NIAO (2020): Impact Review of Special Educational Needs.

[893] Ibid. p.1.

The report drew attention to disparities between the Department of Education's predictions regarding the proportion of children within SEN of approximately 2% and the reality that children with SEN accounted for 5.5% of the school population[894]. The report:

- noted that the importance of early identification of a child's needs and appropriate intervention is widely recognised;
- noted that significant delays persist[895];
- reminded the Department of the requirement of a consistent approach to the identification, assessment, and provision for all children with SEN and concluded that there is no evidence that this requirement is being met in schools;
- recommended that the Education and Training Inspectorate (ETI) should assess whether schools are applying a clear and consistent approach to identifying and providing for children with SEN[896].

The work of NIAO cross referenced the rights-based review of Special Educational Needs provision in mainstream schools (2020) undertaken by the Northern Ireland Commissioner for Children and Young People (NICCY)[897].

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[894] Ibid. para 5, p.2 (accessed 8 December 2021).

[895] Ibid, para 7, p.3.

[896] Ibid, paragraph 6, pp.2-3.

[897] NICCY (2020): Too Little Too Late (accessed 8 December 2021).

The aim of the review was to ascertain whether the needs of children with SEN were being met. The review concluded that the education system is under extreme pressure and was finding it difficult to respond to the scale and complexity of SEN[898].

The review raised the following concerns:

- an overall lack of transparency in the provision of SEN[899];
- the significant under-resourcing of SEN[900];
- a significant rise of 48% in the overall number of children with SEN between 2004/05 and 2020; and an increase in the number of children with statements of 60% in the same period[901];
- fundamental weaknesses in the current system for the provision of SEN[902];
- the detrimental impacts for children with SEN in mainstream schools when their needs are not identified and supported[903];
- significant delays at all levels of the process from the identification of the child's needs, provision or support and service, information and guidance and assessment of the child's progress[904];

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[898] Ibid.
[899] Ibid, p.10.
[900] Ibid, p.11.
[901] Ibid, p.6.
[902] Ibid, p.13.
[903] Ibid, p.8.
[904] Ibid, p.8.

- the lack of opportunities for children to be involved in the SEN process[905];
- the lack of early identification as major failing of the system[906];
- the failure to meet statutory timescales with respect to issuing of statements and recommending that the source of delays be identified and addressed[907];
- concerns regarding the format, content, specificity, and accuracy of statements[908];
- concerns that decisions are made in the context of funding available rather than the needs of the child[909];
- the absence of clear and accessible information for parents, carers, and stakeholders[910];
- reports of unmet needs[911];
- insufficient capacity within schools to meet the rising numbers of children with SEN[912];

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[905] Ibid, p.12.
[906] Ibid, p.8.
[907] Ibid, p.10.
[908] Ibid, p.10.
[909] Ibid, p.11.
[910] Ibid, p.11.
[911] Ibid, p.8.
[912] Ibid, p.9.

- concerns regarding the adequacy of SEN provision in early years settings[913];
- concluded that the system was under extreme pressure and faced challenges in responding to the scale of need and the complexity of issues which children with SEN were presenting with[914].

The rights-based review recommended the introduction of a new framework for the provision of SEN which is adequately resourced. The review proposed 40 recommendations which included that the external review of education proposed within the 'New Decade New Approach' agreement[915] should include a review of the structure and effectiveness of the Education Authority in meeting the needs of children with SEN[916]. Participants in the qualitative research to inform this report disclosed frustrations at the amount of bureaucracy which they experienced as parents in trying to access education for their children. They told us about the lack of appropriate facilities for their children:

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[913] Ibid, p.9.
[914] Ibid, p.6.
[915] UK Government (2020): New Decade New Approach, p.7.
[916] NICCY (2020): Too Little Too Late, p.121 (accessed 8 December 2021).

> “*Access to education for disabled people in Northern Ireland is shocking, whilst there are framework and nice documents and expressed commitment to inclusion in education practice would show that those with a disability have an inordinate number of hoops to jump through to access their right to education.*
>
> *There is a significant lack of proper public toileting and changing facilities for those with disability. It is preventing those with disability participating fully in society. Why would you go out and socialise or shop when you may have to use a dirty floor to change, a significant lack of dignity - just not good enough”.*
>
> **Male carer, aged 40-44.**

The Expert Panel on Educational Underachievement, established by the Department of Education, published an interim report in April 2021[917]. The report noted that special educational needs was one of the biggest challenges facing children in education. The Panel referred to the assessment and statementing process as lengthy and complex, leading to delays in the needs of children being addressed with detrimental impacts upon their education and wellbeing.

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[917] Department for Education (2021): Expert Panel on Educational Underachievement in NI (accessed 5 November 2021).

The report noted the importance of early assessment, highlighting that parents have had to resort to private assessments which have not been formally recognised. Despite the Panel referring to special educational needs as an area of significant challenge, it is not listed in the key themes which have emerged from the panel's work.

There continues to be an attainment gap between children with and without special educational needs[918]. The attainment gap has reduced 46 to 23 percentage points between SEN 1-4 pupils and those with no SEN for those obtaining 5 GCSEs A*-C[919]. Whilst the educational achievements of children with SEN are improving, there has been no strategic evaluation of the support provided to these children to ensure the best possible outcomes.

Participants in the qualitative research informing this report told us of the impact of ongoing segregation in schools upon the lives of d/Deaf and disabled children:

> *"Disabled kids today are in the wrong schools, there's not enough placements. They aren't being pushed to their abilities and are way behind academically, socially plus being bullied because they are different.*

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[918] ECNI (2017): Educational Inequalities in Northern Ireland .

[919] EA (2018): Audit of Inequalities, paragraph 1.3, p.3 .

> *Not enough is being done with this within our schools our governments and our legal systems we must continuously fight for their basic human rights to education. It has a severe detrimental impact on every aspect of their well-being".*
>
> **Disabled woman carer with long-term health condition, aged 40-44.**

Northern Ireland has advanced anti-bullying legislation within schools. The Addressing Bullying in Schools (NI) Act (2016)[920] received Royal Assent in 2016, although implementation was temporarily stalled following the collapse of the political institutions. The Act came into effect on 1 September 2021. The Act defines bullying as act which includes but is not limited to the repeated use of verbal, written or electronic communication, any or other or act, or any combination of those by a pupil or group of pupils against another pupil or group of pupils with the intention of causing physical or emotional harm to that pupil or pupils[921].

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[920] Addressing Bullying in Schools Act (Northern Ireland) 2016 (accessed 2 January 2021).

[921] Ibid, Chapter 25, section 1.

Schools are now required to record all incidents of bullying and alleged bullying. There are no provisions in the Act to specifically address bullying behaviour towards children with disabilities. Guidance issued by the Department makes reference to disability as one of the motivations for bullying behaviour which must be recorded[922]. Guidance also outlines circumstances in which d/Deaf and disabled children may be not intending to demonstrate bullying behaviour[923].

Participants in the qualitative research informing this report told us of their experiences of bullying and assault in school:

> "*It's been a while since school for me, but I was bullied nonstop, and my brother was as well. I was nearly assaulted once, if not for some nondisabled students who I had formed an acquaintance with me. They intervened in time. The teachers do what they can, but it never goes away, educating kids about disability though would help".*
>
> **Disabled man care long-term health condition, aged 16-24.**

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[922] DE (2021): Addressing Bullying in Schools Act (Northern Ireland) 2016: Statutory Guidance for Schools and Boards of Governors, p.25 (accessed 11 December 2021).

[923] Ibid, p.13 and p.25 (accessed 11 December 2021).

The Department of Justice (DoJ) has commissioned the Council for the Curriculum, Examinations and Assessment, (CCEA) to review the primary and post primary curriculum with respect to reducing hate and ensuring that the curriculum adequately addresses disability, racism, sectarianism, homophobia, transphobia, and religion to increase understanding of diversity and reduce the negative impact of prejudice-based bullying[924].

It is understood that the review will:

- review existing materials/resources to establish the extent of the curriculum and responsible structures and increase understanding and awareness of the impact of prejudice, hostility, and hatred in relation to the six categories of hate crime;
- identify gaps and improvements in current provision and how these might be addressed, including teacher training to enable awareness raising with confidence and consistency;
- consider whether the issue of online/cyber bullying in the context of contributing to prejudice, hostility, and hatred to the six categories of hate crime, is adequately addressed;
- review existing materials/resources and consider how they might be brought together for easier access for schools;

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[924] DoJ (2019): Review of Hate Crime Legislation launched, paragraph 16.60, p.621 (accessed 11 December 2021).

- identify areas of good practice in inclusivity and developing positive attitudes[925].

This project has yet to be published due to delays associated with school closures during the pandemic[926]. There is not presently an accurate figure available for the number of disabled children in Northern Ireland [927]. The Northern Ireland Executive, in failing to collect this information, is failing to implement Article 31 of the UNCRPD which relates to gathering appropriate data. Without this data, the Government cannot properly measure progress in implementing children's rights under the UNCRPD, including the right to education.

Right to Education Case Study 1

The Children's Law Centre (CLC) provided legal representation for a Primary 3 child registered in a mainstream school who has autism and severe social, emotional, and behavioural difficulties. The school and parents sought accommodations for the child to enable full time education but required support from the Education Authority (EA). The child had been suspended five times and had faced expulsion.

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[925] Ibid, paragraph 16.63, pp.621-622.
[926] Ibid, paragraph 16.65, p.622.
[927] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.110 (accessed 10 October 2021).

The EA repeatedly refused to give the child a statutory assessment or a statement to enable him to access a full time assistant and autism-specific support so that he could attend full time. Instead, the child was placed on a severely restricted school day from Primary 1 onwards, going in for part of the morning session with a Behaviour Support Assistant. This continued for a very prolonged period with little or no positive progress for the child. CLC filed a Disability Discrimination Claim against the EA for disability discrimination in the exercise of its statutory functions.

Before the hearing the EA, provided the support that had been requested to enable the child to attend school. The SENDIST[928] upheld the discrimination claim. The remedy for discrimination for this child who had suffered sustained and prolonged informal exclusion, sanctioned by the EA, was a written apology. Such endemic unlawful practices by the EA and by a wide range of schools are continuously reported to CLC and other stakeholders. An ability to claim compensation would have a deterrent effect as well as providing more adequate redress for successful claimants[929].

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[928] Special Educational Needs and Disability Tribunal.

[929] Disability Action Case Load 2020.

Right to Education Case Study 2

CLC provided advice and assistance to a young person with a visual impairment. The school had failed to put in place reasonable adjustments such as preparing all written materials in the correct enlarged format in advance, failing to highlight the edges of external steps, failure to make access arrangements for examinations, and failure to use assistive technology. The child was unable to access his lessons and was unable to meet his potential. CLC attended a meeting with the child and the school. The difficulties had included a lack of resourcing to the school to support it in meeting the child's needs and a lack of confidence, knowledge, and experience about how to employ inclusive practices effectively and how to physically create the correct formats for the child's lessons. All the issues were resolved when the correct support for the school and the child were arranged. Many educators in Northern Ireland are not sufficiently resourced or given time and training to enable them to adapt quickly to implement inclusive practices. Training and adequately resourced specialist support services are required across the whole of Northern Ireland to enable the education system to progress in terms of disability equality for pupils[930].

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[930] Disability Action Case Load 2020.

Colleges and Universities are required to make reasonable adjustments to ensure that d/Deaf and disabled people do not experience disadvantage. The colleges fulfil this obligation by making funding available to support students with a learning difficulty and/or a disability (SLDD) through the Additional Support Fund (ASF). The fund allows colleges to give students technical and personal support. This allows them to gain maximum benefit from their courses by removing barriers to study. Examples of technical support include specialised equipment, such as braillers, specialist software and hearing loops. Personal support includes specialist tutors/advisers, such as hearing or visual impairment tutors, interpreters, classroom assistants and note takers. The level of support given depends on both the nature of the disability and the course of study[931].

Universities and colleges providing higher education must make provision for students with disabilities. Support given by colleges and universities can include:

- accommodation adapted for the needs of students with disabilities;
- professional care staff;
- help from volunteers.

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[931] Ni Direct (ND): Disability support at college (accessed 21 December 2021).

Each university or college should publish a 'disability statement' setting out how it gives support. There are many actions universities can undertake to help students with disabilities, including:

- offering course materials in Braille and other accessible formats;
- making sure buildings and facilities are accessible;
- encouraging flexible teaching methods;
- giving support during exams;
- allowing additional time to complete courses.

Disabled Students' Allowances offer extra financial help for students who have an impairment, health condition or a specific learning difficulty like dyslexia[932]. Although the needs and rights of disabled students as learners in higher education are officially recognised, there remains a gap between changes guaranteed by legislation and actual support and accommodation available in higher education institutions[933]. Research has shown that aside from physical barriers such as access to buildings, and access to learning materials, disabled students frequently experience restricted social networks, and experience higher risk of failure and drop-out than do nondisabled students[934].

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[932] NI Direct (ND): Disability support in higher education.

[933] Lane, L. (2017): Am I being heard? 'The 'voice of 'students with disability in higher education: A literature review (accessed 21 December 2021).

[934] Lang, L. (2015): Responsibility and participation in transition to university–voices of young people with disabilities, *Scandinavian Journal of Disability Research*, *17*(2), pp.130-143 (accessed 21 December 2021).

Furthermore, even when higher education institutions (HEIs) provide dedicated disability support services, resources for these services remain smaller than existing need[935]. Thus, even as HEIs become more inclusive of d/Deaf and disabled students, students with disability continue to perceive barriers to education. These perceptions may be the result of both actual differences in physical environments and/or the treatment of students in the classroom, and the inability of educators to understand and be sensitive to and inclusive of them in teaching styles and content.[936]

d/Deaf and disabled students who participated in the qualitative research to inform this study, told us about their experiences and the challenges which they faced in terms of accessing University education:

> *"I believe that many public institutions are ignorant to the rights and laws that protect disabled people. I've experienced ableism and discrimination when asking for renovations in a university to be changed. 7 months later they finally fixed the doors to their original accessible state.*

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[935] Fuller, M., Georgeson, J., Healey, M., Hurst, A., Kelly, K., Riddell, S., Roberts, H. and Weedon, E., (2009): Improving disabled students' learning. *London and New York: Routledge*.

[936] Lane, L., (2017): Am I being heard? 'The 'voice of 'students with disability in higher education: A literature review (accessed 21 December 2021).

I think too many cannot be bothered to educate themselves on disabled people's rights and thus we have so much discrimination daily.”

Disabled man carer with long-term health condition, aged 16-24.

The Disability Strategy Expert Advisory Panel proposed the following recommendations:

- establish an independent review on informal exclusions from school in NI;
- establish an independent review on the extent to which restraint and seclusion are 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 the 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;
- the provision of GCSE sign language[937].

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[937] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.93-94 (accessed 10 October 2021).

The authors of this report propose the following additional recommendations:

- policies and programmes should exist which ensure **that all** d/Deaf and disabled people have the same right to required support;
- regulations to provide for appeal for suspensions under Article 33 of the Education and Libraries (NI) Order 2006 should be progressed to ensure that there is a right to appeal;

  Teacher Education should include mandatory disability training (including sign language) and be accessible.

Article 25: Health

> *"The cut in the block grant from Westminster to Northern Ireland means that in real terms, the budget for Stormont has been slashed drastically. This has meant a squeeze in the budget for care in the community. There are not enough carers, and they are not paid enough. In terms of mental health support, it is non-existent. In my part of Belfast, the waiting list for accessing therapy is 5 years. It is completely unacceptable, and it is killing people and limits their ability to live meaningful independent lives".*
>
> **Disabled woman**

Article 25 of the UNCRPD states that State parties should recognise that d/Deaf and disabled people have the right to the enjoyment of the highest standard of health without discrimination on the basis of disability. Article 25 requires State Parties to take all appropriate measures to ensure access to healthcare services by people with disabilities which are gender sensitive including health related rehabilitation.

Article 25 requires State Parties to:

- provide d/Deaf and disabled people with the same range, quality, and standard of free or affordable healthcare programmes as those provided to others. This includes reproductive healthcare services and population-based health programmes;
- provide healthcare services which are required by d/Deaf and disabled people specifically with respect to their disability including early identification and intervention, services to minimise further disability including among children and older persons;
- provide healthcare services as close as possible to people's own communities including rural areas;
- require healthcare professionals to provide care of the same quality to people with disabilities as to other on the basis of free and informed consent by raising awareness of human rights, dignity, autonomy and the needs of people with disabilities through training and ethical standards for public and private healthcare;
- prohibit discrimination against d/Deaf and disabled people in the provision of health insurance and life insurance;
- prevent discriminatory denial of healthcare, health services, food, and fluids on the basis of disability[938].

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[938] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 25.

The right to health has been enshrined across the international human rights treaties through Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICCPR). The right to health includes the right to access healthcare, to ensure that everyone has the highest standards of physical and mental health. Article 25 of the UNCRPD should be read in conjunction with Article 12 ICCPR which protects the right of an individual to provide consent for medical treatment and for this decision to be respected by medical professionals[939].

The UNCRPD Committee, in its (2017) concluding observations, highlighted the following concerns with respect to Article 25:

- uneven access to healthcare;
- systemic, physical, attitudinal, and communicative barriers which prevent d/Deaf and disabled people from accessing mainstream health services;
- barriers to privacy for d/Deaf and disabled people regarding the management of personal health related data;
- multiple barriers to accessing sexual and reproductive healthcare services and insufficient information and education on family

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[939] McSherry, B. and Waddington, L. (2017): Treat with care: the right to informed consent for medical treatment of persons with mental impairments in Australia, Australian Journal of Human Rights, 23(1), 109.

planning in accessible formats for d/Deaf and disabled people and especially women and girls;

- reports of cases in which no attempt was made to resuscitate persons with intellectual or psychosocial disabilities;
- the suicide rate of d/Deaf and disabled people, particularly in NI[940].

The right to the highest standard of attainable healthcare is of significant concern to d/Deaf and disabled people in Northern Ireland [941]. d/Deaf and disabled people are more likely to experience health inequalities, major health problems and have a lower life expectancy in comparison with their non-disabled counterparts[942].

Significant reform of the healthcare system is required if healthcare is to be accessible and responsive to the needs of d/Deaf and disabled people. For example, Mencap have 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

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[940] 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, CRPD/C/GBR/CO/1, paragraphs 54 and 55.

[941] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations, p.94 (accessed 10 October 2021).

[942] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.19.1, p.24.

with a learning disability is ill or in pain, for example, by focusing on their disability[943]. There are concerns regarding the over-medicalisation of disability, which is associated with disability being perceived as a medical condition without due regard to the societal and structural factors that prevent the full inclusion of people within society[944].

d/Deaf and disabled people face significant barriers in accessing primary health care services[945]. Participants in the qualitative research to inform this report were vocal on the barriers in accessing GPs and other health services citing financial challenges within the health service as a cause of key concern:

> "*Financially, it is almost impossible. The health service is on its knees and support for chronic conditions is gone. If you are lucky enough to get a GP appointment, you will likely get a locum who is reluctant to change a treatment. Second class service for disabled people. Social care is also almost non-existent.*

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[943] Mencap (ND): Treat me Right (accessed 2 January 2020).

[944] Shakespeare, T. (1996): Disability, identity and difference, in Barnes, C. and Mercer, G: Exploring the divide: Illness and identity, The Disability Press.

[945] Department for Communities (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.95 (accessed 10 October 2021).

> *I have complex mental ill health, the system is continuously overwhelmed so after being seen, you are discharged with the proviso to come back if things get worse.*
>
> **Disabled woman, aged 40-44.**

Access to healthcare is even more pertinent in the context of the ongoing Covid-19 pandemic. Research conducted by Disability Action on the impact of Covid-19 on d/Deaf and disabled people in Northern Ireland demonstrated that many respondents experienced 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[946]. Demand for services, such as GP care, has increased and is anticipated to continue to rise after the pandemic subsides[947].

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[946] Disability Action (2020): The impact of Covid-19 on disabled people in Northern Ireland, p.5 (accessed 10 October 2021).

[947] RAISE (2021): Suicide in Northern Ireland (accessed 16 December 2021).

The ability to access health treatment based upon informed consent is essential to protect the right to health. The use of a proxy of next of kin or staff in disability service providers is non-compliant with the UNCRPD[948]. This process persists in NI[949]. There is evidence of 'Do Not Resuscitate' orders being applied inappropriately to d/Deaf and disabled people by medical professionals[950].

Right to Health Case Study

There is evidence to suggest that children with complex support requirements are not receiving an adequate standard of healthcare. A parent of a child with a learning disability has been campaigning for 13 years for her child ('Matthew') to have an adequate bed and proper access to hospital facilities when being admitted to hospital.

The Chief Executive of a local Health Trust suggested that this was a matter for a parent support group rather than mainstream health care or the responsibility of the hospital:

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[948] Ibid, 94.

[949] BMA (2020): Adults with incapacity in Scotland and Northern Ireland (accessed 2 January 2022).

[950] BBC News (2021): People with learning disabilities 'living a nightmare' (accessed 16 December 2021).

> *“There is a parent support group who have provided parent's beds, TVs, and other items to improve the environment for children and parents. Plans are in place in consultation with the Parents Support Group to fund a suitable bed and cocoon for the ward. The floor bed comes with bumpers and a mattress similar to the the one you have at home. It also lowers right to the floor, if needed, and opens at both sides for easy access and will be ideal for Matthew should he require admission to our ward again*”[951].

The child in this case had been diagnosed with Lennox Gastaut Syndrome and had required in-patient care at a local hospital at least once a year or more for the last 13 years.

For the first 4 years of the child’s life, he was admitted to hospital at least once a month because his medical needs had been such that they required regular visits to hospital and his mother described him ‘a frequent flyer’. Despite advance warning from his mother prior to his admittance to hospital presenting with seizures the hospital was often ill prepared to deal with some or all the issues relating to his treatment and care.

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[951] Extract from response letter from Chief Executive from a Health & Social Care Trust in Northern Ireland to a parent seeking a proper bed for her child (June 2020).

Past and current failings by health and social care services have included:

- failure to provide a secure, safe, and comfortable bed for Matthew during his hospital visits specific to his support and safety requirements;
- no effective, consistent protocol into providing a suitable hoist for Matthew to assist him into bed and on one occasion Matthew and his mother had to wait 45 minutes for a hoist to be transferred from another area of the hospital. During that period Matthew had wet himself as a result of the seizures and was left without a change of clothes for the entire time;
- no accessible changing room or shower facilities on the hospital ward.

His mother had to be always with him to hold him and ensure her he is safe on the bed available to him. Otherwise, he would be at serious risk of injury without ongoing support and supervision. His mother, a social worker and healthcare professional, who managed a respite care centre for people with learning disabilities, praised the dedication of the nurses who had looked after her son during his many visits to the hospital. She also applauded the nurses for their charitable efforts to raise money for beds that children with complex support requirements need but nonetheless believes the hospital health care system failed her son.

The current arrangements for her son's care are contrary to the hospital's statutory obligations to uphold his right to an adequate standard of health care, on a par afforded to other non –disabled children[952] . Disability Action and the Northwest Forum for Disabilities are also aware of cases similar to this case study in hospitals across in NI[953].

Mental health is recognised as one of the four most significant causes of ill health and disability in Northern Ireland along with cardiovascular disease, respiratory disease, and cancer[954]. Northern Ireland is currently experiencing a mental health crisis[955]. Northern Ireland has a higher prevalence of mental ill health (by 25%) and a lower per capita spend on mental health (£160) than England (£220) or Ireland (£200)[956]. There is a significant funding gap in mental health provision[957]. There is a lack of provision for people experiencing mental health crisis[958].

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[952] Ibid.

[953] Northwest Forum for Disabilities Case Load 2021.

[954] Wilson, G., Montgomery, L., Houston, S., Davidson, G., Harper, C. and Faulkner, L. (2015): Regress? React? Resolve? An Evaluation of Mental Health Service Provision in Northern Ireland, page v. (accessed 31 January 2022)

[955] The Irish Times (2021): North braced for mental health crisis as a direct result of the pandemic, 29 June 2021 (accessed 10 October 2021).

[956] ECNI (2021) Response to the consultation by the Department of Health on the draft Mental Health Strategy 2021-2031, paragraph 1.27, p.6.

[957] Belfast Telegraph (13 May 2021): Mental health crisis: Patients are sleeping on chairs, says Swann (accessed 27 March 2022)

[958] Ibid.

Those with severe and enduring mental illness live up to 20 years less than others because of poor physical health[959]. More than 2,400 adults and over 260 children and young people are currently waiting longer than three months to be seen by a mental health specialist. More than 700 adults and 90 children / young people waiting longer than a year[960]. Northern Ireland has a 25% higher overall prevalence of mental health conditions than England – 1 in 5 adults here have a mental health condition at any one time[961]. Inequality gaps for mental health indicators have narrowed. Despite this, admissions for suicide and self-harm are higher within the most deprived areas[962]. More than 20% of young people are experiencing significant mental health problems by the time they turn 18. 17% of men and 32% of women aged 35-44 show signs of depression[963].

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[959] John, A., McGregor, J., Jones, I., Lee, S.C., Walters, J.T.R., Owen, M.J., O'Donovan, M., DelPozo-Banos, M., Berridge, D. and Lloyd, K. (2018): Premature mortality among people with severe mental illness - New evidence from linked primary care data, Schizophrenia Research. 199: pp.154-162.

[960] The Irish Times (2021): North braced for mental health crisis as a direct result of the pandemic, 29 June 2021 (accessed 10 October 2021).

[961] AMH (2018): Mental Health in Northern Ireland (accessed 10 October 2021).

[962] Ibid.

[963] Ibid.

There are significant concerns about the high suicide rate in Northern Ireland. Interpreting suicide data is inherently difficult and reliable data is needed. Previously, Northern Ireland was said to have the highest rates of suicide in the UK. However, Northern Ireland suicide statistics between 2015 to 2018 have been reviewed following an anomaly detected in the data series[964].

70% of people who die by suicide in Northern Ireland are not known to mental health services. A quarter of suicide inquiries in the UK showed that the individual died within three months of discharge from in-patient care. In Scotland, 35% died before the first review appointment, with figures of 40% for England and Wales; and 66% in Northern Ireland[965]. Research indicates that one in eight children in Northern Ireland report having suicidal thoughts or having attempted suicide. Men are more likely to die by suicide than women, although more women attempt suicide. Suicide rates in the most deprived areas are three times higher than the least deprived areas[966].

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[964] RAISE (2021): Suicide in Northern Ireland (accessed 16 December 2021).

[965] Ibid.

[966] RAISE (2021): Suicide in Northern Ireland (accessed 16 December 2021).

In 2018, it was reported that over 750 young people aged between 16 and 24 died by suicide in the UK and Ireland[967]. The National Confidential Inquiry into Suicide and Safety in Mental Health concluded that Northern Ireland had the highest rate of suicide in young adults within the UK[968].

Risk factors may be compounded by peer pressure, bullying, the influence of social media, academic stress, eating disorders, discrimination regarding sexual orientation, gender identity, and ethnicity, amongst many others[969]. In 2020, 13,348 referrals were made to Child and Adolescent Mental Health Services[970].

The increased mental health burden associated with the COVID-19 pandemic is likely to be profound and felt for many years. There is evidence emerging that the mental health of younger people in particular has been disproportionately affected[971]. A UK-wide study suggests that

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[967] Ibid.

[968] NCISH (2021) Annual report 2021: England, Northern Ireland, Scotland and Wales, paragraph 1, p.5 (accessed 31 January 2022).

[969] Ibid.

[970] NI Assembly Question AQW 14125/17-22. Mr Gerry Carroll (People Before Profit Alliance - West Belfast): To ask the Minister of Health to detail the number of young people presenting to child and adolescent mental health services in 2020; the number that received support. Referrals figures include Step 2, Step 3, Eating Disorders, Drug and Alcohol Mental Health Service, Crisis and the Regional Family Trauma Centre. Answered on 15/02/2021 (accessed 27 March 2022).

[971] Matthias, P., Hope, H., Ford, T., Hatch, S., Hotopf, M., John, A., Kontonpantelis, E., Webb, R., Wessely, S., McManus, S. and Abel, K. (2020): Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population (accessed 16 December 2021).
BBC News NI (2021): Covid-19 having 'devastating effect' on children (accessed 16 December 2021).

this group has experienced an increase in suicidal thoughts since the pandemic began[972].

Professor Siobhan O'Neill was appointed Mental Health Champion by the Department of Health in September 2021, having occupied the role in an interim basis from the June 2020[973]. The Champion is tasked with ensuring that the voices of people who struggle with poor mental health are heard and influence policy and strategy.

Health Minister Robin Swann launched the publication of the new Mental Health Strategy 2021-2031 on 29 June 2021[974]. The strategy includes a commitment to provide enhanced and accessible mental health services for those who need specialist mental health services, including d/Deaf and disabled children and young people. The strategy states that the services must be able to cater for those with disabilities, including physical and sensory disabilities, ASD and intellectual disabilities and must include help and support for parents and families[975].

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[972] O'Connor, R., Wetherall, K., Cleare, S., McClelland, H., Melson, A., Niedzwiedz, C., O'Carroll, R.E., O'Connor, D.B ., Platt, S., Scowcroft, E., Watson, B., Zortea, T., Ferguson, E. and Robb, K. A. (2021): Mental health and well-being during the COVID-19 pandemic: Longitudinal analyses of adults in the UK COVID-19 Mental Health & Wellbeing study, The British Journal of Psychiatry, 218(6), pp.326-333 (accessed 16 December 2021).

[973] DoH (2021): Mental Health Champion appointed, 8 September 2021 (accessed 2 Nov 2021).

[974] DoH (2021): Mental Health Strategy 2021-2031 (accessed 13 December 2021).

[975] Ibid, Action 7, VIII.

The strategy places an emphasis upon early intervention[976] and includes a commitment to develop an action plan which will include targeted approaches to groups more likely to be adversely affected by mental ill health including people with a physical or sensory disability and persons with an intellectual disability[977].

The Department of Health concedes that across NI, targets for access to services are regularly missed. Almost 2,000 people are waiting more than 9 weeks for access to adult mental health services, 240 children and young people are waiting more than 9 weeks for core CAMHS services and more than 900 people are waiting more than 13 weeks for psychological therapies[978].

The draft mental health strategy outlines the barriers to mental health services and in particular those experienced by marginalised groups who are considered to be at higher risk of mental health challenges due to social exclusion, isolation, communication barriers and societal stigma[979].

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[976] Ibid, paragraph 45, p.26.

[977] Ibid, paragraph 54, p.31.

[978] Department of Health (2021): Mental Health Strategy 2021-2031 consultation draft, paragraph 16, p. 11 (accessed 31 January, 2022).

[979] Ibid, paragraph 12, p. 10.

The strategy:

- places an emphasis upon parity of esteem between physical and mental health;
- commits to ensuring equality and equity of access to mental health provision with a focus on recognising and addressing individual needs[980].

The strategy proposes:

- the development of a year-on-year action plan for mental health promotion;
- significant improvements in primary care mental health services, greater responsibility for GPs, working with GP federations including the roll out of psychological therapy hubs and additional investment to increase access to therapy;
- improved integration between statutory, community and voluntary sectors;
- the creation of a single mental health service with structures in place to deliver regional consistency, quality, and access across NI[981].

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[980] Ibid, paragraph 18, p.11.

[981] Department of Health (2021): Mental Health Strategy 2021-2031 consultation draft (accessed 31 January 2022).

The impact of the strategy is limited by the lack of a clear delivery plan and clarity regarding which aspects of the health service are responsible for actions.

Health and Wellbeing 2026: Delivering Together[982] is likely to have a significant impact upon the lives of d/Deaf and disabled people. It is essential that the proposals to transform healthcare are delivered in a manner which addresses the obligations of the UNCRPD.

Concerns with respect to Article 25 have also been discussed within the commentary in this report with respect to Articles 9, 10, 11, 12, 14, 15, 16, 17, and 26.

The Disability Strategy Expert Advisory Panel proposed the following recommendations:

- 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;

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[982] Department of Health (2017): Health and Wellbeing 2026 - Delivering Together (accessed 2021).

- 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 to develop disability human rights and equality training which should be mandatory for healthcare providers and professionals [983].

The authors of this report propose the following recommendations:

- a dedicated and well-resourced strategy to address health inequalities which includes a timescale for implementation with key deliverables and milestones;
- investment in mental health provision combined with a strategy to remove barriers of access and which increases the provision of community mental health services.

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[983] DfC (2020): Disability Strategy and Expert Advisory Panel: Report and Recommendations. pp.97-8 (accessed 10 October 2021).

Article 26: Habilitation and rehabilitation

Article 26[984] requires State parties to take effective and appropriate measures including peer support to enable d/Deaf and disabled people attain and maintain maximum independence; full physical, mental, social, and vocational ability and full inclusion and participation in all aspects of life. State parties are required to organise, strengthen, and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education, and social services to ensure that services and facilities:

- begin at the earliest possible stage and are based on the multi-disciplinary assessment of individual needs and strengths; support participation and inclusion in the community and all aspects of society, are voluntary, and are available to d/Deaf and disabled people as close as possible to their own communities, including rural areas.

State parties are required to promote:

- the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services;

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[984] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 26 (accessed 4 November 2021).

- the availability, knowledge, and use of assistive technologies, designed for d/Deaf and disabled people, as they relate to habilitation and rehabilitation.

Habilitation and rehabilitation are understood as a set of interventions required to assist d/Deaf and disabled people towards full participation within their environment[985]. The Convention on the Rights of d/Deaf and disabled people recognises a cross-sectoral approach to rehabilitation. While habilitation and rehabilitation also figure as components of other Convention rights relating to health, employment and education, Article 26[986] establishes a unifying framework for the provision of coordinated and comprehensive habilitation and rehabilitation services which are embedded in human rights through respect for free and informed consent, non-discrimination, participation, availability, affordability, and accessibility.

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[985] OCHR (2019): Report on habilitation and rehabilitation under article 26 of the Convention on the Rights of Persons with Disabilities (accessed 21 December 2021).

[986] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 26 (accessed 4 November 2021).

In order to implement Article 26[987] of the Convention, States should take measures to review their legal and policy frameworks; ensure cross-sectoral coordination; develop a multidisciplinary and trained rehabilitation workforce; establish funding mechanisms to ensure adequate access to affordable rehabilitation services; conduct awareness-raising with a human rights-based approach; and carry out reliable research and data collection for improving the quality of, and access to services.

Transforming Your Care'[988] engages the social and economic right to health in the context of progressive realisation within available resources. This means that 'available resources' constitutes a valid limit on the extent to which the right can be realised at the present moment, but it cannot mean a 'falling back' or retrogression with respect to the right. Unfortunately, ongoing challenges with respect to budgets are limiting progression within this area[989].

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[987] Ibid.

[988] DoH (2011): Transforming your care (accessed 21 December 2021).

[989] DoF (2021): Budget Consultation (accessed 21 December 2021).

There are concerns regarding access to rehabilitation[990]. There is limited availability of information with respect to access to habilitation and rehabilitation. ‘Struggling to Recover’ was launched by the Stroke Association in February 2019[991].

The report reveals that:

- stroke survivors in Northern Ireland receive approximately one-third of the recommended 45 minutes of physiotherapy, occupational therapy, and speech therapy per day;
- 45% of stroke survivors feel abandoned when they leave hospital;
- 90% of stroke survivors feel their emotional needs are not met;
- 78% of stroke survivors feel the care and support they receive at home is poor or very poor;
- 98% of family carers say they sometimes find it difficult to cope[992].

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[990] RCOT (2018): Getting my Life Back: Occupational therapy promoting mental health and wellbeing in Northern Ireland (accessed 22 December 2021).

[991] Stroke Association (2019): Stroke survivors in Northern Ireland “struggling to recover” (accessed 22 December 2021).

[992] Ibid.

In NI there are a number of specific programmes targeted towards specific disabilities. There is concern however, that that access to services can be time limited due to resources or people are waiting for long periods before being able to access services. There are concerns about how different areas of service interact to ensure that people have access to the appropriate services at the right time[993].

Parents of children with sight loss have raised specific concerns about access to habilitation services for children and young people. In a report from Blind Children UK, research showed that 54% of parents of a visually impaired child up to four years did not receive any help to develop their child's co-ordination[994]. England has already passed legislation for the provision of habilitation services and Scotland is due to legislate. However, in NI there is no statutory right to habilitation services for children and young people[995].

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[993] Disability Action (2017): Alternative Report on the Implementation of the Convention on the Rights of Persons with Disabilities in Northern Ireland, paragraph 2.1-2.20, p.36.

[994] Belfast Telegraph (2015): Parents of visually-impaired children speak out over lack of specialist care (accessed 2 January 2022).

[995] Ibid.

The authors of this report propose the following recommendations:

- a review of access to habilitation and rehabilitation services in order to benchmark provision, reduce waiting times and increase provision;
- introduce a statutory right to habilitation services for children and young people.

Article 27: Work and employment

> *"I have to continue to prove that I am disabled as my managers will not make adjustments that would make my working life any easier. My employer seems to restrict the opportunities for disabled people or persons with health issues. The majority of promotion opportunities require you to agree to work full time and are not open to people who are unable to work full time. My employer is struggling to meet the requirements to have a certain quota of disabled people in higher positions but is unwilling to make the changes required to actually accommodate such candidates to apply and succeed".*
>
> **Disabled man with a long-term health condition, aged 55-59.**

Article 27 requires State parties to recognise the right of d/Deaf and disabled people to work on an equal basis with others. Access to employment is core to the realisation of rights and freedoms and key to health and independence.

The UNCRPD identifies eleven actions which include:

- prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
- enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
- promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining, and returning to employment;
- employ persons with disabilities in the public sector.

Article 27 states that these actions should be promoted and safeguarded by taking appropriate steps including legislation[996]. The UNCRPD Committee, in its (2017) concluding observations, raised concerns regarding:

- the persistent employment gap and pay gap for work of equal value affecting people with disabilities, especially women and persons with psychosocial and/or intellectual disabilities and people with visual impairments;
- the insufficient affirmative action measures and provision of reasonable accommodations to ensure that people with disabilities can access employment in the open labour market despite the obligations contained in the EU Directive 2007/78/EC on non-discrimination in the workplace;
- the process related to the Employment and Support Allowance and the fact that the Work Capability Assessment emphasises a functional examination of skills and capabilities, rather than recognising the interactions between disability and the societal barriers facing people with disabilities.

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[996] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 27 (accessed 4 November 2021).

The UN Committee recommended that the State Party, in close collaboration with DPOs and in line with the Committee's report on its inquiry concerning the UK and NI carried out under Article 6 of the Optional Protocol to the Convention[997]:

- develops and decides upon an effective employment policy for d/Deaf and disabled people with the aim of securing decent work for disabled people and ensures equal pay for equal work of equal value especially for d/Deaf and disabled women and people with psychosocial and/or intellectual abilities and persons with visual impairments and to ensure the effective monitoring of these matters;
- ensures that reasonable accommodation is provided to all d/Deaf and disabled people who require it in the workplace, that regular training on reasonable accommodation is available to employers and employees without disabilities and that effective sanctions are in place in cases of the denial of reasonable accommodations;
- ensures that the legal and administrative requirements of the process to assess working capabilities, including the Work Capability Assessment are in line with the human rights model of disability, that those who complete the assessments are suitably

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[997] UN General Assembly (2006) Optional Protocol to the Convention on the Rights of Persons with Disabilities, A/RES/61/106, Annex II (accessed 24 February 2022).

> qualified and duly trained in the human rights model of disability; and that assessments take into consideration work related as well as other circumstances. The State party is required to ensure that the adjustments and support necessary to access work including financial support are provided and are not subject to sanctions conditional upon carrying out job seeking activities[998].

Access to employment plays an essential role in the realisation of other rights and freedom including health, independence, participation, and inclusion. d/Deaf and disabled People are at disadvantage to non-disabled peers in accessing, retaining, and progressing within employment in Northern Ireland[999].

d/Deaf and disabled people continue to be less likely to be in employment than non-d/Deaf and disabled people within Northern Ireland[1000]. There are complex social and systemic barriers to people with disabilities accessing employment and enjoying career progression and development[1001].

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[998] 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, CRPD/C/GBR/CO/1, paragraphs 56 and 57 (accessed 4 November 2021).

[999] Department for Communities (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.81 (accessed 10 October 2021).

[1000] Ibid, p.81.

[1001] All Party Group on Disability (2016): 'Ahead of the Arc' – A contribution to halving the disability employment gap (accessed 4 November 2021).

The participants in the qualitative research to inform this report told us that they are uncomfortable discussing their needs with their employers and that there is not enough assistance and support to overcome barriers to employment:

> "*I have mental health issues on top of my physical health conditions and don't feel comfortable raising them with my employer. I also have a teenage son with ASD, and I worry about the impact of stigma on him in relation to accessing employment and education as he grows. At present, children, and adolescents with ASD are not always being afforded the assistance and support they require in relation to educational achievement and access to employment".*
>
> **Disabled woman carer, with long-term health condition, aged 45-49.**

Northern Ireland has the lowest rate of employment for d/Deaf and disabled people in the UK. Figures for April-June 2021 report that 36.4% of d/Deaf and disabled people are in employment compared to 80.3% of people without a disability[1002]. This means that at the time of writing, the Disability Employment Gap was 43.9%.

[1002] NISRA (2021): Quarterly Labour Force Survey Tables – August 2021 (accessed 16 December 2021).

This is wider than the figure of 41.2% quoted within the Disability Strategy Expert Advisory Panel for the first quarter of 2020[1003]. 52.3% of d/Deaf and disabled people were in employment in 2021 in the UK[1004], and the figure for Europe is 50.6%[1005]. The UK Government has set a target to seek that one million disabled people are in work by 2027[1006]. Participants in the qualitative research to inform this report have told us that the disability employment is too wide, and that action needs to be taken to resolve this:

> "*The gap in employment between those who are disabled and not disabled is excessive. Employers need educated and supported to change approaches, but the Social Security Benefits system also needs adjustment to allow greater support for those trying to enter or re-enter work".*
>
> **Non-disabled woman carer, aged 45-49.**

[1003] Department for Communities (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.81 (accessed 10 October 2021).

[1004] House of Commons Library (2021): Disabled people in employment (access 16 December 2021).

[1005] IED (2021): The Status of Employment and disability in the EU in 2021 (accessed 16 December 2021).

[1006] DWP (2017): Strategy seeks one million more disabled people in work by 2027 (accessed 16 December 2021).

The disability payment gap is widening having increased by 20% between 2019 and 2020 from £1.65 to £2.10. This means that a d/Deaf and disabled worker working 35 hours per week could earn £3,822 per year less than a non-disabled worker[1007]. The pay gap for d/Deaf and disabled women is nearly nine percentage points higher than the gender pay gap. d/Deaf and disabled women are paid 36% less than non-disabled men[1008].

The main factors contributing to the pay and employment gap for d/Deaf and disabled people are:

- a higher proportion of d/Deaf and disabled people are in part time work. Part-time work, particularly in the private sector is paid less per hour than full-time work;
- d/Deaf and disabled people are over represented in lower paid jobs including caring and leisure, sales, customer services, and other services;
- d/Deaf and disabled people are under-represented in senior and managerial roles;
- some d/Deaf and disabled people leave education earlier than non-disabled people;

[1007] TUC (2020) Disability pay and employment gaps 2020 (accessed 1 February 2022).

[1008] Ibid.

- when d/Deaf and disabled people have the same qualifications the pay gap persists[1009].

Trade Union Congress (TUC) assert that the Disability Pay Gap is linked to unlawful discrimination, structural barriers, and negative attitudes[1010]. TUC recommend the following measures to address the disability pay gap:

- mandatory disability pay gap reporting for all employers with more than 50 employees;
- a duty on employers to produce targeted action plans identifying the steps which they will take to address the disability pay gap[1011].

The Equality Commission NI has highlighted concerns expressed by d/Deaf and disabled people about job security, about money and redundancy arising from the ongoing Covid-19 pandemic[1012]. The pandemic has also widened the disability employment gap, particularly for those with mental health challenges.

[1009] TUC (2020): Disability pay and employment gaps 2019 (accessed 1 February 2022).

[1010] TUC (2020): Disability pay and employment gaps 2020 (accessed 1 February 2022).

[1011] TUC (2020): Disability pay and employment gaps 2019 (accessed 1 February 2022).

[1012] ECNI (2020): People with disabilities must not be left behind by response to COVID-19 (accessed 10 October 2021).

Participants in the qualitative research underpinning this report have told us of the challenges which they face in accessing employment:

> *"I have two degrees a Bachelor and honours degree and a Masters. Yet no-one will employ me due to my disability. They get away with it because the feedback or reasons given are enough to satisfy a glancing review.*
>
> *The only reason my brother is working is because the company he is with are all sufferers of mental health challenges as well and use their lived experience to help others as it is a social enterprise. Without them he would never work anywhere due to his health. I cannot work in conventional jobs due to my disabilities and access needs.*
>
> *Places would rather turn me away then spend money so I can do a job. I'm now having to try get another degree, fingers crossed, in teaching as I believe it's the only route left open to me. Otherwise, I will be on benefits for the rest of my life or until I am forced to take that life. This is the harsh but the brutal reality of the situation.*
>
> **Disabled man carer with long-term health condition, aged 16-24.**

d/Deaf and disabled people are more likely to be working in industries such as hospitality, retail and catering which have been most affected by the pandemic and are more likely to be facing redundancy than non-disabled people[1013].

Further efforts are required to ensure that all appropriate measures are in place to support d/Deaf and disabled people's right to work on an equal basis with others[1014]. An analysis of factors affecting the employability of d/Deaf and disabled people in NI concluded that there was a complex range of factors; including the attitude of employers; workplace accessibility including transport; a lack of qualifications and skills notably for d/Deaf and disabled people leaving compulsory education with low qualifications; personal attitudes towards work, the absence of financial incentives; a lack of policy integration and joined up thinking in service provision; and the availability, sustainability and the quality of the employment[1015]. Action will require the coordination of policies across a range of government departments.

[1013] UK Parliament (2021): Disability Employment Gap: Impact of the Coronavirus pandemic, paragraph 4, p. 126.

[1014] The Independent (2021): Calls for 'radical new approach' to reduce disability employment gap (accessed 16 December 2021).

[1015] McQuaid R., Graham H., Shapira M. and Raeside R. (2013): DELNI Economic Inactivity Strategy: Literature Review Project, Edinburgh Napier University (accessed 16 December 2021).

Participants in the qualitative research informing this report told us that they felt they were a drain on society and resources:

> "*Disabled people seem to be considered a drain on society. Employers only seem to want to recruit people who can work full time and seem to view anyone with a health issue/disability as a drain on resources; that they will need extra support, which to the employer equals cost; and that the person would be unreliable and be off work sick more often".*
>
> **A disabled man with a long-term health condition, aged 55-59.**

There are higher rates of disability in Northern Ireland (more than 1 in 5 people) in comparison with the rest of the UK[1016]. Northern Ireland has the lowest rate of employment for d/Deaf and disabled people with only 37.8% in employment compared to 80.1% for non-d/Deaf and disabled people[1017]. This is much lower than the EU rate of employment for d/Deaf and disabled people which is 50.8%[1018].

[1016] ONS (2019): Disability and employment, UK: 2019 (accessed 10 October 2021).
[1017] Ibid.
[1018] European Disability Forum (2020): European Human Rights Report 2020: Poverty and Social Exclusion, p.48 (accessed 10 October 2021).

Austerity measures and Covid-19 has negatively impacted has created further challenges for d/Deaf and disabled people in accessing employment[1019]. d/Deaf and disabled workers, especially those with mental health issues, are more likely to work in part-time jobs, non-permanent jobs, and in jobs with zero hours contracts[1020]. They are also more likely to work in the sectors that have been hardest hit by the Covid-19 pandemic and the economic response to it. The implications of the end of the Job Retention Scheme[1021] introduced in response to Covid-19 have yet to be explored[1022].

[1019] Clifford, E. (2020): The War on Deaf and disabled people: Capitalism, Welfare and the Making of a Human Catastrophe (London: Bloomsbury).

[1020] Roberts, J., Bryan, M., Bryce, A., Rice, N. and Sechel, C. (2021): Written evidence from Jennifer Roberts, Mark Bryan, Andrew Bryce, Nigel Rice, Cristina Sechel' University of Sheffield and University of York (DEG0132) (Evidence Summary) (accessed 10 October 2021).

[1021] The Coronavirus Job Retention Scheme (CJRS) applied from 1 March 2020 and ended on 30 September 2021. The scheme provided grants to employers so they could retain and continue to pay staff during coronavirus related lockdowns, by furloughing employees at up to 80% of their wages. Under the Coronavirus Job Retention Scheme (CJRS), the government provided a grant to UK employers to cover up to 80 per cent of the wages of employees whom they continue to pay but who would otherwise have been laid off as a result of the coronavirus (COVID-19) crisis. The original version of the scheme ran from 1 March 2020 to 30 June 2020 and has now been replaced by phase two of the scheme which runs from 1 July 2020 to 31 October 2020. This new phase is known as "flexible furlough", the principal difference being that, in phase two, furloughed staff are allowed to work on a part-time basis with employers claiming a grant under the scheme for their non-working hours.

[1022] UK Government (2020): Claim for wages through the Coronavirus Job Retention Scheme (accessed 10 October 2021).

Findings from health and labour economists from the University of Sheffield and York as part of the Health Foundation Social and Economic Value of Health Research Programme (2021) indicate that the end of the Job Retention Scheme may impact disproportionately on d/Deaf and disabled people[1023].

d/Deaf and disabled workers (and particularly those with mental health disability) are not distributed evenly across industrial sectors. The preponderance of workers with mental health disability in the hardest hit sectors means that they are particularly vulnerable to job losses caused by Covid-19 and the economic response to it. This means that the mental health disability employment gap is likely to widen in the future as the economy adjusts and many jobs in these sectors are permanently lost[1024].

[1023] Roberts, J., Bryan, M., Bryce, A., Rice, N. and Sechel, C. (2021): Written evidence from Jennifer Roberts, Mark Bryan, Andrew Bryce, Nigel Rice, Cristina Sechel' University of Sheffield and University of York (DEG0132) (Evidence Summary) (accessed 10 October 2021).

[1024] Roberts, J., Bryan, M., Bryce, A., Rice, N., Sechel, C. (2021): Written evidence from Jennifer Roberts, Mark Bryan, Andrew Bryce, Nigel Rice, Cristina Sechel' University of Sheffield and University of York (DEG0132) paragraph 5, (accessed 10 October 2021).

Disability discrimination is the most common enquiry to the Equality Commission (49.5% of enquiries were disability related in 2020/21)[1025]. Failure to make reasonable adjustments is a common concern in Northern Ireland[1026]. The failure to make reasonable adjustments has led to an estimated loss of 35,000 to 48,000 jobs in the UK[1027].

Legal protections for d/Deaf and disabled people are found within the Disability Discrimination Act (DDA) 1995.

This report has extensively referenced the gaps between equality protections within NI and the UK due to the fact that the Equality Act 2010 does not apply to NI. The legislative gap is a significant factor contributing to ongoing inequality and discrimination experienced by d/Deaf and disabled people in the labour market. The DDA (1995) does not provide acceptable protection for d/Deaf and disabled people in employment[1028].

[1025] ECNI (2021): Annual Report and Accounts, p.18 (Accessed 24 October 2021).

[1026] Disability Action (2016): Hard at Work: Employment and Disability in NI

[1027] All Party Group on Disability (2016): 'Ahead of the Arc' – A contribution to halving the disability employment gap, paragraph 8, p.7 (accessed 4 November 2021).

[1028] Department for Communities (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.83 (accessed 10 October 2021).

There is limited information available which demonstrates the lived experience of d/Deaf and disabled people with respect to employment[1029]. Whilst available data regarding disability employment in Northern Ireland provides an indication of rates of participation, it does not capture the complexity of the individual experiences of people with disabilities[1030].

Their voices (when listened to) speak of ongoing stress and anxiety in relation to overcoming the most basic of disability related barriers in employment[1031]. To date there has been an absence of co-designed programmes to support d/Deaf and disabled people to access employment[1032]. There are concerns regarding the level of resource directed towards supporting the employment of d/Deaf and disabled people[1033].

[1029] Department for Communities (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.85 (accessed 10 October 2021).

[1030] Ibid.

[1031] Disability Action (2015): Hard at Work: Employment and Disability in Northern Ireland (accessed 2 January 2022).

[1032] Department for Communities (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.85 (accessed 10 October 2021).

[1033] IMNI (2017): Disability Rights in Northern Ireland: Supplementary Submission to inform the CRPD List of Issues on the UK, p.8 (accessed 10 October 2021).

The DfC Disability Employment Stakeholder Forum established in 2016[1034] with responsibility for developing a Disability Employment Strategy in Northern Ireland. It is co-chaired by the Department and a DPO and includes representatives from the supported employment sector.

The Department's Disability Employment Stakeholder Forum has changed direction in recent times to focus on what are described as strategic issues, focusing more or less exclusively on actions and measures prioritised by the Department. Accordingly, the participation and meaningful involvement of d/Deaf and disabled people in the development of employment measures has not been significant[1035].

[1034] Clanrye Group (No Date): Northern Ireland Disability Stakeholders Forum (accessed 4 November 2021).

[1035] Assessment provided by the Northwest Forum of People with Disabilities Representative Co-Chair of the Disability Stakeholder Forum (November 2021). The limitations set by the Department to exclude operational issues at the highest level limits the involvement of disabled people who want to address real life barriers to employment. There have only been two disabled person led workshops in 6 years and there is no evidence that disabled people's views are being reflected in employment policy initiatives being addressed at the Employment Stakeholder Forum. In 2016 the sector representatives asked for research to be conducted in order to explore the benefits of supported Employment for Disabled People this request 5 years later has never been actioned.

The European Social Fund (ESF) represents a positive example of an employment support programme for d/Deaf and disabled People. Concerns have been raised by disability stakeholders regarding the impact of Brexit on access to EU Structural Funds including the European Social Fund[1036], particularly with respect to the supported employment sector.

Under the terms of the UK-EU Withdrawal Agreement[1037] the UK is not eligible to apply for structural funds after the 2014-2020 budget cycle but may complete funding claims for projects supported in this budget cycle up to the end of 2023[1038]. NI received €510m, or €280 per person from the ERDF and ESF combined[1039]. Therefore, the loss of access to this funding stream is likely to present significant challenges to the region. ESF has been the primary source of funding for employment projects for d/Deaf and disabled people in NI.

This funding will cease in March 2022. Finance Minister Conor Murphy allocated £26.5mn of Covid-19 funding to extend the ESF programme until the end of March 2023[1040].

[1036] Ibid, p.8.

[1037] Department for Exiting the European Union (2019): New Withdrawal Agreement and Political Declaration, Policy Paper (accessed 10 October 2021).

[1038] Institute for Government (2021): European structural funds: the UK Shared Prosperity Fund (accessed 10 October 2021).

[1039] Ibid.

[1040] NIAO (2021): Overview of the Northern Ireland Executive’s Response to the COVID-19 Pandemic - Second Report, p.22 (accessed 1 February 2022).

At the time of writing match funding had been received by projects supported by DfC to progress the ESF programme[1041]. Projects whose match funding is provided by DfE had yet to receive confirmation that an allocation would be made[1042].

The UK Government has proposed replacing EU Structural Funds with a new UK Shared Prosperity Fund (UKSPF) which is due to be launched in April 2022[1043]. The November 2020 spending review described the overall purpose of the UKSPF as ‘to level up and create opportunity across the UK for people and places’. The spending review stated that UKSPF spending will ramp up to around £1.5bn a year and ‘at least match current receipts from EU structural funds’. It will also ‘operate over multiple years’ to provide certainty and enable long-term planning[1044]. Achieving Net Zero carbon emissions and clean growth have been recognised as priorities[1045].

[1041] DfC (2022): Hargey announces £1.5M funding to local employment and education projects (accessed 24 February 2022).

[1042] DfE (2021): ESF Information Memo 28/21 - Call 3 Match Funding (accessed 2 February 2022).

[1043] Ibid.

[1044] UK Government (2020): Wales and the Shared Prosperity Fund: Priorities for the replacement of EU structural funding: Government response to the Committee’s Fourth Report of Session 2019–21.
Institute for Government (2021): European structural funds: the UK Shared Prosperity Fund (accessed 10 October 2021).

The UKSPF will consist of two main portions. The first will “target places most in need” such as post-industrial towns and deprived rural and coastal communities, in which it will be focused on:

- supporting local skills and vocational training tailored to local needs, such as work-based training;
- investment in transport improvements, digital connectivity, neighbour, and housing improvements, and civic, cultural, and sporting facilities;
- investment for local business, including to support innovation, adoption of new technologies, and a low-carbon transition[1046].

The second part of the UKSPF will be targeted at people rather than places and will deliver employment and skills programmes to improve outcomes for ‘specific cohorts of people who face labour market barriers’[1047]. Whilst the November 2020 Comprehensive Spending Review referred to the Adult Education Budget and Early Years in the context of the UKSPF, there was no reference to disability.

At the time of writing, there is no guarantee that the UKSPF will provide a similar standard of support to d/Deaf and disabled people accessing employment as the ESF.

[1046] Ibid.

[1047] HM Treasury (2020): Spending Review 2020, CP 330, paragraph 3.19, p.37 (accessed 10 October 2021).

The Disability Strategy Expert Advisory Panel proposed the following recommendations:

- 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;
- 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:
    1. funding for Supported Employment model for d/Deaf and disabled people furthest from the labour market;

2. 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);
3. access to work to support d/Deaf and disabled people in training and work experience and greater public awareness programme[1048].

In addition, the authors of this report propose the following recommendations:

- mandatory disability pay gap reporting for all employers with more than 50 employees;
- a duty on employers to produce targeted action plans identifying the steps which they will take to address the disability pay gap[1049].

[1048] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, pp.87-88 (accessed 10 October 2021).

[1049] TUC (2020) Disability pay and employment gaps 2019 (accessed 1 February 2022).

Article 28: Adequate standard of living and social protection

> "*Financial support is difficult to access. For example, PIP requires a long, handwritten form to be completed. You cannot complete it online or type, which meant I had to ask someone to write the form out for me, sharing details I would rather have kept private. The assessment process was conducted by someone who told me that I would not be helping myself if I extended my family and that the Government would penalise me in the assessment if they knew I wanted more children. This is discrimination! Many complaints about the assessment process focuses on what you can't do rather than what you are able to do. The whole process was quite humiliating and dehumanising."*
>
> **Disabled woman with long-term health condition, aged 45-49.**

Article 28 requires State Parties to recognise the rights of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, and housing.

State Parties are required to recognise the rights of disabled people to the continuous improvement of living conditions and to take steps to safeguard and promote the realisation of the this right without discrimination on the basis of disability.

State Parties are required to recognise the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of discrimination and to take appropriate steps to realise this right including the following measures:

- to ensure equal access to clean water services and affordable services and devices and other assistance for disability related needs;
- to ensure access by d/Deaf and disabled people particularly women and girls, and d/Deaf and disabled older people to social protection and poverty reduction programmes;
- to ensure access by persons with disabilities and their families living in poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance, and respite care;
- to ensure access by persons with disabilities to public housing programmes;

- to ensure equal access by persons with disabilities to retirement programmes[1050].

The UNCRPD Committee concluded, in its 2016 Inquiry Report into the impact of welfare reform in the UK, that welfare reform represented a grave and systemic violation of the rights of d/Deaf and disabled people[1051]. The Committee drew this conclusion based on the rationale and philosophy underpinning the UK Government's approach to welfare reform.

The Committee were concerned that the reforms were justified in the context of austerity measures to achieve fiscal and budgetary consolidation, the notion that the d/Deaf and disabled people are better off in work than on benefits, that taxpayers need to be treated with fairness and the numbers of disabled people depending on social security needed to be reduced and that the tightening of sanctions and conditionality of social benefits was a legitimate tool for incentivising and moving d/Deaf and disabled people into work.

[1050] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 28 (accessed 4 November 2021).

[1051] BBC (2016): UN: 'Grave' disability rights violations under UK reforms, 7 November 2016 (accessed 1 November 2021).

Among the recommendations they specified that particular attention be paid to disabled people at higher risk of exclusion such as persons with learning disabilities and those with mental health issues (psycho-social disabilities).

The Committee found that welfare reform had reduced the household income of d/Deaf and disabled people in receipt of benefits[1052] due to the transition from Disability Living Allowance to Personal Independence Payments (PIP), changes to housing benefit, changes to child support, sanctions and complexities associated with accessing mitigation packages[1053].

Extensive evidence shows that d/Deaf and disabled people continue to face serious regression of their rights to an adequate standard of living and social protection, and to live independently in the community[1054].

The UNCRPD Committee, in its (2017) concluding observations, were concerned about the impact of austerity measures and welfare reform measures introduced as consequence of the financial crisis in 2008/9, which resulted in severe economic consequences for d/Deaf and disabled people and their families, particularly children with disabilities.

[1052] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.39 (accessed 10 October 2021).

[1053] Ibid.

[1054] UKIM (2018): Government's response to the UN report on the Convention on the Rights of Persons with Disabilities: Briefing by the UK Independent Mechanism, Westminster Hall Debate 20 June 2018. p.1 (accessed 14 October 2021).

These included: increased reliance on food banks; the negative impact of reductions in social support; reductions in unemployment allowance, PIP and Universal Credit on the standard of living of d/Deaf and disabled people as well as insufficient compensation for disability related costs. The Committee was also concerned about the tightening of eligibility criteria and local differences in social protection and support. The Committee noted that the introduction of Personal Independence Payments had led to a reduction in the number of recipients of disability-related allowances. There had also been negative impacts on the standards of living for d/Deaf and disabled people and their families. The Committee also expressed concern about the detrimental impact of Employment Support Allowance Conditionality and sanctions on persons with disabilities and the limited access to reconsideration and repeal procedures[1055].

[1055] 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, CRPD/C/GBR/CO/1, paragraph 58 (accessed 4 November 2021).

The Committee recommended that the State party:

‘… *introduce, adopt and implement legislative frameworks to ensure that social protection policies and programmes across the State party secure income levels for all persons with disabilities and their families, by taking into account the additional costs relating to disability … ; carry out a cumulative impact assessment, based on disaggregated data, of the recent and forthcoming reforms of the social protection system for persons with disabilities, and in close collaboration with organizations of persons with disabilities define, implement and monitor measures to tackle retrogression in their standard of living and use the cumulative impact assessment as a basis for policy development across the State party; … [and] conduct a review of the conditionality and sanction regimes concerning the Employment and Support Allowance, and tackle the negative consequences on the mental health and situation of persons with disabilities.*’[1056]

[1056] Ibid, paragraph 59.

The UNCRPD Committee were concerned, in their (2017) concluding observations, that welfare reforms were justified in the context of austerity measures to achieve fiscal and budgetary consolidation; the notion that the disabled people are better off in work than on benefits; that taxpayers need to be treated with fairness and the numbers of disabled people depending on social security needed to be reduced; and that the tightening of sanctions and conditionality of social benefits was a legitimate tool for incentivising and moving disabled people into work[1057]. Among their recommendations the Committee specified that particular attention should be paid to disabled people at higher risk of exclusion such as persons with learning disabilities and those with mental health issues (psycho-social disabilities)[1058].

Neither the UK Government nor the Northern Ireland Executive have addressed the concerns raised by the UN Committee[1059]. The UK Government rejected the UN Committee's recommendations on social security reform in its 2016 inquiry report.[1060]

[1057] 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, CRPD/C/GBR/CO/1, paragraphs 58 (accessed 4 November 2021).

[1058] Ibid.

[1059] UKIM (2018): Government's response to the UN report on the Convention on the Rights of Persons with Disabilities: Briefing by the UK Independent Mechanism Westminster Hall Debate, 20 June 2018, p.1 (accessed 14 October 2021).

[1060] Ibid, p.2.

UKIM and IMNI remain concerned about the lack of UK Government progress in protecting the rights of people in the UK and social protection in particular[1061]. UKIM's submission to the UN Committee[1062] highlighted that:

- high proportions of d/Deaf and disabled people are resorting to food banks[1063];
- a higher proportion of d/Deaf and disabled people are disadvantaged by the introduction of the Employment and Support Allowance, particularly the negative impact of the Work Capability Assessments and ESA conditionality on the mental health of claimants[1064];
- d/Deaf and disabled people are disproportionately affected by the new sanctions regime[1065];
- there is a continued regression in disabled people's right to live independently in the community, including the risk of re-institutionalisation posed by funding cap policies[1066].

[1061] Ibid, p.1.
[1062] UKIM (2017): Disability Rights in the UK (accessed 14 October 2021).
[1063] Ibid, paragraph 49, p.47.
[1064] Ibid, paragraph 57, p.50.
[1065] Ibid.
[1066] Ibid, paragraph 5.4, p.18.

d/Deaf and disabled people are 50% more likely to live in poverty and disadvantage than those who do not have a long-standing illness[1067]. Households with one or more d/Deaf and disabled members faced large and disproportionately negative impacts from tax and benefit changes made between 2010 and 2018[1068].

78% of d/Deaf and disabled people not in receipt of disability social security benefits come from households experiencing the highest levels of deprivation. According to the Trussell Trust Foodbank Network, which operates 36 foodbanks across Northern Ireland, more than 62% of working age d/Deaf and disabled people are referred to their network for support[1069].

23% of households with a disability were losing more than a quarter of their income on repaying debt or loans, compared to 14% among households not affected by disability whilst 41% of d/Deaf and disabled people were in debt to the the UK Department of Work and Pensions (DWP)[1070].

[1067] UKIM (2018): Progress on disability rights in the United Kingdom. p.21. (accessed 10 October 2021).

[1068] EHRC (2020): The cumulative impact of tax and welfare reforms, p.15.

[1069] BBC (2021): Coronavirus: Food bank need for NI children 'at historic level', (accessed 2 January 2022).

[1070] The Trussell Trust (2021): The State of Hunger: it’s not right that disabled people are being forced to turn to food banks.

The Trussell Trust also found that even if some people were successful in applying for and receiving disability benefits such as DLA and PIP, for many it was not enough to prevent hardship and material deprivation in many households indicating that disability benefits, for those fortunate enough to meet the threshold for entitlement, was not sufficient to meet the extra costs associated with disability and ill health[1071].

Research participants identified specific challenges associated with the benefit system, and offered potential solutions:

> “*The current benefits system is designed to be as restrictive as possible. The assessment process is demeaning and not at all person-centred. Perhaps if disabled people were involved in co-designing and co-delivering the benefits system it would be much more effective and supportive than it currently is.*
>
> *The current system can create a disincentive to people trying to move towards employment, as the rules around part-time and permitted work are such that people can often be worse off in work than on benefits.*

[1071] Ibid.

> *There is also a lot of fear that if someone tries taking up employment, but finds they can't cope with the demands, they will be penalised for leaving work and becoming 'wilfully unemployed', resulting in a loss of benefits."*
>
> **Female non-disabled carer, aged 60-64.**

There is considerable evidence which demonstrates the adverse impact of welfare reform on the right of d/Deaf and disabled people to live independently and to an adequate standard of living and social security[1072]:

- d/Deaf and disabled people have not been effectively consulted or engaged on the welfare reforms [1073];
- welfare cuts are planned in the immediate future to reduce further spending on disability benefits[1074]

[1072] UKIM (2018): Progress on disability rights in the United Kingdom, p.21 (accessed 10 October 2021).

[1073] UK Parliament (2014): Welfare Reform (Sick and Disabled People) (accessed 18 December 2020).

[1074] DWP (2021): Shaping future support: the health and disability green paper. See, for example, paragraph 302 (accessed 18 December 2021).

- families, where someone has a disability, have lost an average of £2,000 per year as a result of changes to disability related benefits[1075];
- the National Audit Office (2018) concluded that the Department for Work and Pensions (DWP) has not done enough to support vulnerable claimants who have faced hardship as a result of changes to Universal Credit[1076];
- reductions in disability benefits – from April 2017 have continued;
- those d/Deaf and disabled people claiming Employment Support Allowance and Universal Credit assessed as being in the work-related activity group in receipt of both benefits through the work capability assessment have had their income reduced by £30 per week losing their disability premiums within both benefits[1077];
- young people who had previously been allowed contribution-based ESA, even if they haven't paid national insurance contributions also lost their entitlement[1078];

[1075] NIHRC (November 2019): Cumulative Impact Assessment (CIA) of the Impact by Reforms to the Tax and Social Security System in Northern Ireland, see Section Heading 4.2 Impact by Disability Status of Adults and Children in the Household, pages 53-59 (accessed 5 November 2021).

[1076] NAO (2018): Rolling out Universal Credit, paragraphs 2.5–2.11, p.31-33 (accessed 3 November 2021).

[1077] UK Parliament (2019): Ten Years of the Work Capability Assessment (accessed 18 December 2021).

[1078] NI Direct (ND): Changes to Employment and Support Allowance (accessed 18 December 2021).

- those in receipt of contributions-based ESA have had their entitlement to the benefit limited to one year;
- the transfer from DLA to PIP and entitlement to the disability elements of UC through the work capability assessment has continued using the medical interpretation of disability functional tests to assess entitlement, causing significant stress and anxiety to claimants;
- evidence suggests that d/Deaf and disabled people have no trust in the process according to two independent reviews of the PIP process;
- supporting evidence for PIP claims is not being properly evaluated resulting in unfair decisions being made with regard to entitlement;
- the change of circumstances can result in significant loss in benefit entitlement;
- support to d/Deaf and disabled people on UC during the Covid pandemic of £20 per week on UC has been withdrawn increasing the number of people falling into poverty[1079];

[1079] University of Bath (2021): New report reveals hidden complexities of uplift for Universal Credit claimants (accessed 15 December 2021).

- the additional support provided to people on universal credit was not given to those disabled people on legacy benefits, those in receipt of JSA, IS etc[1080];
- the UK Government have been challenged for discriminating against people with mental health issues (psycho-social disabilities) to allow for proper consideration for entitlement to the PIP payment[1081];
- d/Deaf and disabled people feel the conditionality and sanctions regime associated with UC takes little account of their disability and they find themselves applying for jobs that do not take into account the nature of their impairment[1082];
- there is also some evidence to suggest that d/Deaf and disabled people have not only fallen further into poverty but also lost their lives as a result of welfare reform changes[1083];

[1080] Disability News Service (2021): Universal credit uplift failure was 'unfair, unjustified and discriminatory', court hears (accessed 15 December 2021).
[1081] CPAG (2018): PIP and Psychological Distress (accessed 15 December 2021).
[1082] d/Deaf and Disabled Person's Engagement with the Independent Panel on Welfare Mitigations, Chaired by Les Allamby, 15 December 2021.
[1083] The Guardian (2020): Errol Graham is the latest victim of a cruel system – we need a culture shift (accessed 18 December 2021).

- entitlement to PIP, for many, is subject to ongoing assessments every three years on average even where the nature of the impairment is not going to change and disabled people, in these circumstances, are constantly under stress and anxiety having to undergo repeated assessments even though their circumstances are unlikely to change;
- there is some evidence to suggest that d/Deaf and disabled people who are in work receive PIP awards for a limited period or up to three years. There is no evidence to suggest that consideration is being given to the reasonable adjustments d/Deaf and disabled people receive while in employment when considering PIP award entitlements;
- the commitment by the DfC to conduct a cumulative impact assessment as to the overall impact on d/Deaf and disabled people of the welfare reforms[1084];had not been progressed at the time of writing;

[1084] DfC (2020): Disability Strategy Expert Advisory Panel Report, p.41 (accessed 18 December 2021).

- the DfC Disability Strategy Expert Advisory Panel has recommended that the Department for Communities adopt changes to the welfare system being applied in Scotland which adopt a human rights-based approach in consultation and engagement with d/Deaf and disabled people[1085].

Participants within the qualitative research informing this report told us of the impact that the loss of income due to welfare reform has had upon their lives:

> *"The benefit cuts and increased living costs are making it impossible for people with disabilities to just survive. Bedroom tax, UC uplift cut, individualised reduced awards - all designed to reduce income for the most vulnerable who will be most adversely affected by increased heat, light, power, and fuel costs. But no-one cares".*
>
> **Disabled woman, aged 40-44.**

[1085] Ibid, p.42.

A cumulative impact assessment of the impact of tax and social security reforms in Northern Ireland commissioned by the Northern Ireland Human Rights Commission (2019) found a clear relationship between household disability 'score' and the proportion of households losing from the reforms. 32% of households containing no members with functional disabilities lose from the reforms, in comparison to 68% of households with a disability score of four or six or more and 66% of households with a disability score of 5 lose out[1086].

The Equality and Human Rights Commission's (EHRC) analysis of tax and welfare reforms introduced in the GB between May 2010 and January 2018 concluded that their cumulative impact on d/Deaf and disabled people was regressive and that d/Deaf and disabled people were disproportionately impacted upon by public service cuts[1087]. The findings concluded that:

- households with at least one d/Deaf and disabled adult and/or a d/Deaf and disabled child will lose over £6,500 a year (over 13% of their net income)[1088];

[1086] NIHRC (2019): Cumulative impact of tax and social security reforms in Northern Ireland, paragraph 7.2, page 101 (accessed 16 December 2021).

[1087] EHRC (2020): The cumulative impact of tax and welfare reforms, p.15 (accessed 3 November 2021).

[1088] Ibid, p.88.

- d/Deaf and disabled lone parents with at least one disabled child will lose almost £10,000 of their annual net income[1089];
- adults with behavioural difficulties will lose around £2,350 a year[1090];
- adults with learning difficulties will lose around £1,750[1091]
- adults with mental health conditions will lose just over £1,799[1092].

Participants in the research informing this report have told us about the difficult decisions which they faced due to a lack of income:

> *"When you have to decide between eating and heating and have to fight to get equipment you need to live and have no way to improve your life while the government cut what little money you have - it's disgusting".*
>
> **Disabled carer with a long-term health condition**

Financial challenges, poverty and reliance on food banks were key themes which emerged through the qualitative research elements of this study:

[1089] Ibid, p.20.

[1090] Ibid, p.78.

[1091] Ibid, p.78.

[1092] EHRC (2020): The cumulative impact of tax and welfare reforms (accessed 3 November 2021).

> “*The lengthy processes that you have to go through to prove that you really are suffering from lifelong limiting illnesses is inhumane and degrading. Fighting for medication, treatment and services. Disabled people are constantly being judged, frowned upon if they're on benefits. The system needs reformed and quickly far too many people are falling through the cracks. People are living in poverty having to go to food banks struggling to make ends meet. Especially with the rise in electric, gas etc. - everything else goes up - though the disabled and their carers are neglected, living in destitution. It's scary how so many are having to decide whether it's electric or heating to try and stay afloat.”*
>
> **Disabled woman carer with long-term health condition, 40-44.**

The Disability Benefits Consortium has drawn attention to the financial situation faced by d/Deaf and disabled people on legacy benefits facing rising costs for essential items and new costs as a result of changes brought on by the pandemic and the withdrawal of services and support: 82% of d/Deaf and disabled claimants have had to spend more money than they normally would during the pandemic. This is most commonly due to greater food shopping and utility bills, as over half (54% and 53%) of d/Deaf and disabled claimants said these costs had increased significantly.

As a result of these increased costs, two thirds (67%) of d/Deaf and disabled claimants have had to go without essential items at some point during the pandemic; almost half (44%) of d/Deaf and disabled claimants are reporting being unable to meet financial commitments such as rent and household bills[1093].

Access to Advice

d/Deaf and disabled people have reported significant challenges accessing advice and support to obtain their benefit entitlements. During the Covid-19 pandemic key services provided by Advice NI, that should have been available to d/Deaf and disabled people, were suspended for seven months,[1094] from March to September 2020 due to public health concerns.

[1093] The Disability Benefits Consortium (2021): Pandemic Poverty - stark choices facing disabled people on legacy benefit, paragraph 2, p.3 (accessed 16 December 2021).

[1094] An Independent Advice Network suspended all disability related benefit advice during the pandemic. DPOs in rural and urban areas in Northern Ireland undertook to support greater numbers of disabled people applying for key benefits, focused mainly on assisting Personal Independence Payment claimants. The Northwest Forum of People with Disabilities assisted 21 PIP claims and completed 9 applications for PIP during this period.

The View Digital[1095] have detailed the findings of a survey of Northern Ireland's advice workers, highlighting fears for claimants' rights in the 'broken social security system' in Northern Ireland.

Findings showed:

- 75% of cases advice workers anticipated a denial of the minimum essential level of benefits required to access food, housing, and healthcare;
- 11 in every 20 claimants were not able to access professional advice and representation at each stage of the social security assessment process;
- 83% of claimants were not informed by the Department about the criteria used to assess their eligibility for the benefit they applied for.
- 80% of claimants did not fully understand the nature of the assessment process – a figure which rose to 98% of Universal Credit claimants[1096].

[1095] The View Digital (2021): Advice workers fear for claimants' rights in 'broken social security system' in Northern Ireland, 6 September 2021 (accessed 5 November 2021).

[1096] Ibid.

Mitigations

The Northern Ireland Executive and Assembly have the devolved powers to administer social security. However, there are limitations in the capacity to make decisions due to the principle of parity[1097]. As part of the UK's devolution arrangements, responsibility for welfare policy lies with the Northern Ireland Executive but in practice, the Executive has

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[1097] The parity principle in social security in the UK is one of the few forms of parity which has an explicit statutory basis, as set out above in sections 87 and 88 of the NI Act (1998). The duty of 'consultation and co-ordination' has been interpreted by the Department of Social Development (DSD) (and its predecessors) before the introduction of the NI Act 1998. The DSD, now the Department for Communities, explains 'the long-standing principle of parity dictates that an individual in Northern Ireland will receive the same benefits, under the same conditions, as an individual elsewhere in the United Kingdom'. The Department states that, because of this, that 'policy proposals for the NI Welfare Reform Act will therefore largely mirror those contained in the UK Westminster Act' to involve a virtually immutable 'parity principle' between NI and GB social security law.
Section 87 of the NI Act (1998) is a 'consultation and coordination' provision. The wording is, "shall from time to time consult one another with a view to securing that, to the extent agreed between them, the legislation to which this section applies provides single systems of social security, child support and pensions for the United Kingdom". Although there are regular contacts between the DWP and the DSD, these provisions would appear to require consultation between the two Departments before proposals for changes to the system are made. Birrell and Heenan identify the National Insurance Act 1946 as an early example of reciprocal arrangements. It would not be sufficient for the DWP merely to inform the DSD of proposed changes. As such, there ought to be an opportunity, at an early stage, for the DSD to consider and propose variations in any changes 'in the particular circumstances of NI'
The mechanisms set out in section 88 appear to facilitate the outworking of any agreement reached. However, in practice, they have been interpreted to give the DWP and the Treasury an effective veto on any variations in NI social security law.
Source: NICCY (2012) An Examination of Parity Principles in Welfare and Wider Social Policy, paragraph 4 (accessed 16 December 2021).

operated in compliance with the parity principle, with the exception of a limited mitigations package.

The 'Stormont House Agreement[1098]' 'and 'New Decade New Approach' Agreement committed to funding mitigations[1099] which are temporary and complicated to navigate.

A series of mitigations were secured as part of the 'Fresh Start' Agreement[1100]. A Welfare Reform Mitigations Working Group was established to develop proposals to mitigate against the negative implications of Welfare Reform[1101]. The Working Group proposed a mitigation strategy, which was approved by the Executive[1102]. The mitigations package included: withholding the bedroom tax for under occupancy in the social housing sector; and time limited supplementary payments to d/Deaf and disabled people who have their disability benefit award reduced or removed because of the transition from DLA to PIP. Many of the mitigations had an initial timescale of one year[1103].

[1098] Northern Ireland Executive (2015): A fresh start: the Stormont agreement and implementation plan, paragraph 3.5, p.26 (accessed 1 November 2021).

[1099] Northern Ireland Executive (2015): A fresh start: the Stormont agreement and implementation plan, paragraph 3.5, p.26 (accessed 1 November 2021).

[1100] Ibid.

[1101] TEO (2016) Welfare Reform Mitigations Working Group Report (accessed 1 November 2021).

[1102] Ibid.

[1103] Child Poverty Action Groups (No date): Welfare reform mitigation in Northern Ireland, p.17-18 (accessed 1 November 2021).

In 2020, the Minister for Communities committed to extending the mitigations beyond the March 2020 ‘Cliff Edge’[1104]. While the necessary legislation was not passed in time, due to the Covid-19 crisis, the Department for Communities confirmed that payments would continue to be made for all the existing mitigations schemes via contingency arrangements[1105]. A draft Bill to provide for mitigation payments for people affected by the Social Sector Size Criteria policy has been shared with the Executive[1106].

The Department for Communities had cited access to funding and the need for further legislation as key barriers for the continuation of welfare mitigations[1107]. Despite these challenges the Minister for Communities has extended welfare mitigations for a maximum period of 3 years until 31 March 2025[1108]. The decision was made following a period in which the DUP had blocked the extension 39 times[1109].

[1104] Law Centre NI (2020): Cliff Edge Welcomes Minister’s Commitment to Extend Welfare Mitigations But Concerns Remain Over Families Hit by Bedroom Tax and Benefit Cap (accessed 5 November 2021).

[1105] Housing Rights (2020): Welfare Mitigation Payment Update, (accessed 5 November 2021).

[1106] Ibid.

[1107] Department for Communities (2021): Time is running out as Welfare Reform Mitigations Face Another ‘Cliff Edge (accessed 1 November 2021).

[1108] BBC (2021):Welfare reforms: Stormont agrees to extend mitigations (accessed 2 January 2021).

[1109] Ibid.

The Cliff Edge Coalition had previously highlighted gaps within the existing mitigations[1110]. These include:

- Benefit Cap mitigations only protect claimants who were in receipt of the benefit when the mitigation was introduced in 2016. Many low-income families, lone parents and those who have lost employment due to Covid-19 are not eligible to benefit from this mitigation because of this loophole[1111];
- households who move to another social home where they under occupy to the same or greater extent loose entitlement to this mitigation.

The extension of the mitigations closed these gaps ensuring that 600 families with children who were previously denied payments will now receive them[1112].

The Minister appointed an Independent Advisory Panel to review Welfare Mitigation Measures. The Panel does not include representation from a DPO. To mitigate against this, the Chair held an engagement with d/Deaf and disabled people in partnership with Disability Action and the Northwest Forum of People with

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[1110] Ibid.

[1111] Ibid.

[1112] Ibid.

Disabilities[1113]. The Minister, in communication with IMNI, has committed to considering the UNCRPD Committee 2016 Inquiry Report[1114] and 2017 Concluding Comments[1115] into account as part of this review.

[1113] d/Deaf and Disabled People's Engagement with the Independent Advisory Panel on Welfare Mitigations 15 December 2021.

[1114] Committee on the Rights of Persons with Disabilities (2016): 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 (accessed 16 December 2021).

[1115] 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, CRPD/C/GBR/CO/1, paragraphs 58 (accessed 4 November 2021).

Personal Independence Payment

> *"NI have introduced PIP which replaces the old system of DLA. PIP is assessed by non-medical staff who decide if a disabled person is disabled enough to receive it. It is the most cruel system which completely disregards the struggles of disabled people. This is a violation of disabled people's human rights. Furthermore, carers of children with disabilities are being refused disability payments as they are asked to prove how levels of disability impact on their lives. It is cruel and disgusting. Most parents of disabled children struggle to care for their disabled child and work but are refused disability living allowance as the health trusts refuse to provide reports on their children's conditions therefore parent carers struggle to provide evidence. Moreover, the assessors contact schools to confirm a child's needs, which is reported back on by untrained teaching staff. Teaching staff are educators, not medical professionals, they mostly cannot identify certain disabilities. It is a farce and parent carers are struggling to cope."*
>
> **Non-disabled carer, female, aged 45-49.**

4% of individual PIP decisions made between April 2013 and December 2017 were overturned on appeal[1116]. Only 48% of new PIP claims within NI were successful during the period of June 2016 to February 2021[1117]. 27% of claimants who had previously received Disability Living Allowance (DLA) and were reassessed for PIP, were unsuccessful and were left with no access to disability-specific benefits between June 2016 and February 2018[1118].

IMNI have expressed concerns regarding the Social Security (Personal Independence Payments) (Amendment) Regulations 2017[1119]. These concerns have been centred upon the level of anxiety, fear and stress caused by the PIP assessment process, challenges with the evidence process, and the lack of accessibility of the application process[1120].

In December 2017, the High Court found that the rules which distinguish between physical and mental health issues in the award of the mobility aspect of PIP are unlawful and discriminatory against those with mental health issues.

[1116] Ibid.

[1117] DfC (February 2021): Personal Independence Payment (PIP) Experimental Statistics, p.1 (accessed 3 November 2021).

[1118] DfC (2018): Personal Independence Payment Statistics: February 2018 (accessed 3 November 2021).

[1119] The Social Security (Personal Independence Payment) (Amendment) Regulations 2017: explanatory note (accessed 17 December 2021).

[1120] IMNI (2019): Report on the Department for Communities Response to Independent Review of PIP Process and Compliance with Recommendations of the UN CRPD Committee (accessed 16 December 2021).

The Court also found that the rules were in breach of the Human Rights Act (1998). The EHRC put forward the position that the rules are at odds with Article 19 of the UNCRPD. The High Court agreed with this position[1121].

As of May 2021, there were a total of 156,580 people in receipt of PIP in Northern Ireland. 39% of respondents were in receipt of both components of PIP at the enhanced rate,[1122] while 61% of d/Deaf and disabled people received lower levels of financial support against the existing threshold for entitlement[1123]. The Northern Ireland Executive have not repealed the 2017 Personal Independence Payment Regulations. The Department for Communities is continuing to reassess people in receipt of Disability Living Allowance for entitlement to PIP[1124].

[1121] RF v SSWP [2017] EWHC 3375 (Admin), paragraphs 60 and 61 (accessed 17 December 2021).

[1122] DfC (2021): Benefit Statistics Summary Publication (National Statistics) – May 2021 (accessed 5 November 2021).

[1123] DfC (2021): Benefit Statistics Summary Publication (National Statistics) – May 2021 (accessed 5 November 2021).

[1124] Personal Independence Payments (PIP) are a non-means tested tax free benefit that has been replacing DLA for working age claimants since June 2016. Historically the concentration of DLA claimants has been higher in Northern Ireland than in Great Britain. The level of entitlement to PIP depends on the extent to which a claimant's long-term health condition or disability affects their ability to manage daily activities - prepare and cook food, dress and undress, communicate and socialize with others and mobility, a claimant's ability to walk and get around. The PIP award comprises two components, a daily living and a mobility component payable at either a standard or enhanced rate.
Source: UK Parliament (ND): Department of Work and Pensions Inquiries.

Two independent reviews of the PIP assessment process undertaken in Northern Ireland (in 2018[1125] and 2020[1126]), suggest that disabled people have lost trust in the PIP process and the work capability assessment associated with entitlement to employment support allowance. The PIP assessment process is a fragmented process that impacts negatively on both claimants and those who seek to support them. The face-to-face assessment causes fear, anxiety, stress, and frustration. This has a knock-on impact on the health and well-being of claimants, their family and wider support networks, and places even more demands on already stretched services[1127].

Participants within the qualitative research which informs this study were vocal regarding the negative impacts associated with PIP assessments:

> "*Having to prove your disability is so hard. It is degrading. It definitely leads to other health issues (especially mental health issues). If someone has a disability for 10+ years, it is extremely unlikely their abilities will change. Yet they have to prove they are entitled to financial benefits throughout their life - it is a disgrace*"
>
> **Disabled woman with long-term health condition aged 45-49.**

[1125] Rader, W. (June 2018): Personal Independent Payment: An Independent Review of the Assessment Process, Executive Summary of Main Findings, p 1.

[1126] DfC (2021) Second Independent Review of the PIP Assessment Process in Northern Ireland - report and response (accessed 17 December 2021).

[1127] Rader, W. (June 2018): Personal Independent Payment: An Independent Review of the Assessment Process, Executive Summary of Main Findings, p.6.

This finding is also reflected elsewhere in the UK, for example, in the findings of the Work and Pensions Committee 2018 inquiries[1128].

According to the first NI Independent Review of the PIP process, people were being physically sick, having panic attacks, having difficulties with swallowing and breathing during the assessments[1129].

The 2020 Northern Ireland Independent Review noted similarities in the findings from the earlier 2018 Northern Ireland Review and from the findings of the 2018 Work and Pensions Committee inquiry in that there continues to be a lack of trust in the process[1130].

In June 2021, the Northern Ireland Public Services Ombudsman (NIPSO) published the report of an Investigation into assessment for PIP[1131]. The report noted that repeated opportunities were missed by the Department to make the right payment as early as possible in the process. It found that both the Department for Communities and Capita often failed to seek and use further evidence, including that from medical

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[1128] The Work and Pensions Committee Inquiry into the Personal Independence Payments and Employment and Support Allowances Assessments published two reports in January and February 2018 entitled PIP and ESA Assessments: Claimant Experiences and PIP and ESA Assessments which recognise the need for rebuilding claimant trust in the ESA and PIP processes.

[1129] DfC (2020): Independent Review of the Personal Independence Payment (PIP) Assessment Process in Northern Ireland (accessed 17 December 2021).

[1130] Cavanagh, Marie (December 2020): Personal Independence Payment A Second Independent Review of the Assessment Process, paragraph 5.4.10, page 107.

[1131] Northern Ireland Public Service Ombudsman (2021): PIP and the Value of Further Evidence: An investigation by the Northern Ireland Public Services Ombudsman into Personal Independence Payment (accessed 5 November 2021).

professionals, in its assessments[1132]. This meant many claimants had to continually challenge the original decision, often all the way to appeal, before the correct decision was made[1133].

There were 10,000 claimants lodged between April 2019 and June 2021, 60% of which were successful[1134]. The report concluded that the failings constituted systemic maladministration. Key findings from the report included the following:

- the most common reason for not requesting further evidence was that ‘it was unlikely evidence would be obtained within the timescale required’ – even though there were 6 weeks available within which to gain such evidence;
- face to face assessments of claimants was often the primary and, in some cases, the only source of evidence relied upon by Disability Assessors;
- Capita used information on the number of assessment reports completed and submission times to decide on bonuses for Disability Assessors; these had the potential to inhibit the appropriate use of further evidence in making assessments;

[1132] Ibid, p.9.

[1133] Ibid, p.9.

[1134] BBC (2021): PIP: Six in 10 disability claimants win case on appeal (accessed 17 December 2021).

- in a high number of cases where claimants had their PIP decision overturned at the last stage of the Department's internal process, the investigation found numerous examples of evidence relied upon at appeal was either already available to the Disability Assessor or the contact details of those who could provide it were already available;
- despite Capita and the Department's contention that further evidence has a key role in the PIP process, it was often only at the last stage and following the submission of an appeal to the Tribunal that the role of further evidence was elevated;
- too many vulnerable claimants may not have been identified for additional support at the start of the PIP process because of the Department's narrow interpretation of its own guidance;
- many PIP claimants received correspondence from Capita that stated all health professionals they had listed had been contacted, when in-fact this was not the case;
- opportunities for the Department and Capita to systematically improve the quality of assessments and decision making were lost due to an incomplete analysis of the reasons for the overturn of benefit decisions[1135].

[1135] Ibid, p.9.

Many d/Deaf and disabled people are subject to repeat face-to-face assessments on average every three years for the duration of their claim. This includes people with physical disabilities and neurological disabilities, whose health condition is unlikely to change. For example, cerebral palsy is an impairment acquired at birth, yet people with this impairment are subject to three-year reviews to guarantee continuation of their benefit entitlement.

It is of note that in 8 PIP cases known to the Northwest Forum of People with Disabilities, 2 people with cerebral palsy who were unable to work received what are known as 10-year light touch reviews and that in 6 other cases where people with cerebral palsy were in work they received 3-year reviews. There appears to be an inherent bias against d/Deaf and disabled people who are in work and the review period for their claim. It is important to recognise that whatever award is granted to d/Deaf and disabled people in this instance. that cerebral palsy is acquired at birth and its affects are unlikely to change[1136].

[1136] Northwest Forum of People with Disabilities Case Load. Since 2016 the Northwest Forum of People with Disabilities have supported disabled people with their PIP applications including liaison with professional independent advice agencies in 37 cases. They have found that if a disabled person is working, they are more likely to be subject to repeated assessments for PIP on average every 3 years though admittedly the sample size is small and there is no research in this area.

Only those d/Deaf and disabled people who have received a ten-year review are not subject to ongoing repeated assessments but instead will have a light touch review at the end of the ten-year period.

Right to Social Protection Case Study

The case of Mark was reported by the BBC in July 2021[1137]. Mark, (not real name), is an adult with a history of mental health issues, including depression and anxiety. He told disability assessors that he was not able to leave the house on many occasions due to the extent of his anxiety. The Capita assessor asked him: "And would you look at the internet? eBay, Amazon, YouTube?" Mark responded that he would go on YouTube but for "the likes of Amazon, I just don't have the money to buy anything". However, Capita's official report claimed Mark said, "he will surf the internet and shop online". Mark also told Capita he had significant debt problems after being asked whether he pays his bills. He added that the Citizens Advice Bureau had set up a debt management plan to help him. However, Capita wrote in its assessment: "He states he can make simple purchases and understands the value of money. He states he will pay his own bills and has good memory and cognition."

[1137] BBC (2021): PIP disability benefit claims 'misrepresented' by assessors (accessed 5 November 2021).

The Department for Communities heard a "mandatory reassessment" of the scoring during which Mark told the Department he had "a debt management plan with the Citizens Advice Bureau Lisburn for £55,000 worth of debt". However, the Department gave him zero points for his ability to manage complex budgetary decisions. Mark also advised the appeals service he had difficulties washing[1138] and walking because of severe incontinence but was awarded no points in respect of these issues on reassessment.

The Department for Communities stated that the Minister is committed to ending privatisation of the PIP service and bringing it 'in-house' in partnership with the Department of Health but that such a partnership was 'not currently feasible'[1139]. As a result of the Covid-19 pandemic the initial Capita Contract has been extended by the Department to 2023[1140].

[1138] Mark reported not washing himself for up to 10 days at time, how his son helped him to shower and that he had difficulty walking.

[1139] BBC (8 July 2021): PIP disability benefit claims 'misrepresented' by assessors (accessed 5 November 2021).

[1140] The Belfast Telegraph (2021): PIP assessment firm Capita could lose contract in overhaul, Communities Minister Hargey suggests, 24 June 2021 (accessed 5 November 2021).

Capita assert that a sample of claimants are surveyed monthly following their PIP assessment by an independent research company. Since 2017, more than 98% of those surveyed have said they were satisfied or very satisfied with the service[1141]. However, the Northern Ireland Audit Office (NIAO) (2021) Independent Report questioned the veracity of these surveys[1142]. Capita currently pay for surveys to be carried out on the service it provides before the Department makes its decision on a claim. The NIAO found it unusual that the Department does not commission and pay for these surveys directly. Moreover, the timing of the survey may lead to d/Deaf and disabled claimants not fully reflecting their views on the entire service provided by Capita[1143].

A report (2021) by the Northern Ireland Public Services Ombudsman (NIPSO) found that people seeking to have their PIP claims reviewed or seeking an appeal are systematically disadvantaged because of the inadequate and inconsistent gathering of further evidence for progressing a review or an appeal of the PIP decision.[1144]

[1141] Ibid.

[1142] Northern Ireland Audit Office (2021): The Management and Delivery of the Personal Independence Payment Contract in Northern Ireland, paragraph 2.16, p.18 (accessed 5 November 2021).

[1143] Ibid.

[1144] Northern Ireland Public Services Ombudsman (2021): PIP and the Value of Further Evidence: An investigation by the Northern Ireland Public Services Ombudsman into Personal Independence Payment p.260 (accessed 5 November 2021).

At the initial review stage the investigation found further evidence was only requested by Capita Disability Assessors in 35 of 100 claims that were examined in the report[1145].

Other issues identified by NIPSO include inadequate management of information from claimants' health professionals[1146], inadequate recording of the disability assessor's decision-making and the type of assessment used e.g. face to face assessment or paper-based review.[1147] The NIPSO report revealed that of 96 claims recommended for face-to-face assessment, further evidence to determine whether a paper-based review would suffice was only sought for one claimant[1148].

[1145] Ibid, p.9.

[1146] Ibid, p.9.

[1147] Ibid, p.9. A paper-based review provides evidence which already exists to support a disabled person's application, for example, outlining the nature of their impairment and its impact on daily activities and mobility is already well documented without subjecting the claimant to a functional medical type face-to-face assessment which claimants find stressful regardless of the outcome of the process.

[1148] Ibid, page 9.

Evidence suggests, that for some claimants, decisions about the type of assessment they will experience can be the difference between life and death.[1149] There is an absence of records detailing from which to ascertain how PIP decisions are made[1150].

Evidence has demonstrated that PIP assessments may not always accurately present information provided by claimants.[1151] DPOs have suggested that there is an inherent bias against people with mental health issues within the PIP process[1152], an issue highlighted during a successful legal challenge when the court found that the amendments to the mobility component criteria was discriminatory towards those with mental health issues (psycho-social disabilities)[1153].

[1149] Derry Journal (5 March 2021): People have lost their lives as a result of the welfare reforms (accessed 5 November 2021). The Case study refers to a client of the Northwest Forum of People with Disabilities who should have had a paper-based review type of assessment was advised that he would be having face-to-face assessment to evaluate his entitlement for the new Personal Independence Payment. The client became seriously ill at the thought of having a face-to-face assessment and took his own life. The decision to request the claimant to undertake a face-to-face assessment was reversed to a paper-based review but it was the letter itself that triggered the period of illness which resulted in loss of life.

[1150] Northern Ireland Public Services Ombudsman (2021): PIP and the Value of Further Evidence: An investigation by the Northern Ireland Public Services Ombudsman into Personal Independence Payment, p.10.

[1151] DfC (2018): Personal Independence Payment: An Independent Review of the Assessment Process Northern Ireland, p.6.

[1152] Mind (2020): Thousands of people with mental health problems could be missing out on PIP - despite court ruling against DWP (accessed 5 November 2021).

[1153] RF v Secretary of State for Work and Pensions [2017] EWHC 3375 (Admin) Mostyn J, 21 December 2017 (accessed 17 December 2021).
Disability Rights UK (2021): Landmark PIP legal challenge success shows effective use of collaborative public law approach (accessed 5 November 2021).

PIP Appeals Process

The UK Government has spent two billion pounds defending against successful legal challenges, regarding the eligibility and entitlement to PIP by people with mental health difficulties.[1154] Most appeals are won by the claimant at considerable personal cost, including the stress and anxiety to the claimant caused by having to go through appeals process. More than £10 million has been spent by the Department for Communities on processing PIP appeals over the last 3 years.[1155] From April 2019 to June 2021, there were 9,999 PIP related appeals lodged in Northern Ireland and, of these, 5,969 cases (60%) were won by the d/Deaf or disabled claimant[1156]. Furthermore, a PIP award was revised down in only 58 cases[1157]. These statistics highlight a significant and ongoing problem with the PIP assessment process.

[1154] Department for Work and Pensions (2021): Shaping future support: the health and disability green paper, paragraph 268 (Accessed 5 November 2021).

[1155] The Belfast Telegraph (26 July 2021): Over ten Million spent on PIP Appeals over the last three Years (accessed 5 November 2021). Please note the intent of the welfare reforms was to make a 20% saving on disability benefits but in Northern Ireland and UK wide social security spending has increased, partly because of appeals.

[1156] Department for Communities (2021): Benefit Statistics Summary Publication (National Statistics) – May 2021 (accessed 5 November 2021).

[1157] BBC (2021): PIP: Six in 10 disability claimants win case on appeal (accessed 5 November 2021).

Many d/Deaf and disabled people are being forced to appeal[1158] for their rightful entitlement to disability benefits while others are enduring high levels of stress and anxiety due to income uncertainty.

Claimants who wish to dispute the original decision on their PIP are required to seek a 'Mandatory Reconsideration' (MR) of the grounds for the original decision. An MR must be completed before an appeal is made and lodged with the Appeals Service. Only 20% of MRs result in a change of award[1159]. By the end of May 2021, 73,260 MRs had been registered. A total of 69,370 MRs have been cleared by end May 2021. By this point, 79% of MRs resulted in no change to the award. The mandatory award stage is viewed by many disabled people as a further means of further prolonging the assessment process[1160]. Given the significant success rates at the appeal stage, doubts remain about the validity of MR process.

[1158] Northern Ireland Public Services Ombudsman (2021): PIP and the Value of Further Evidence: An investigation by the Northern Ireland Public Services Ombudsman into Personal Independence Payment (accessed 5 November 2021).

[1159] DfC (2021): Benefit Statistics Summary Publication (National Statistics) – May 2021 (accessed 5 November 2021).

[1160] Ibid.

Disability Action is aware from its caseload that many d/Deaf and disabled people do not challenge the award decision beyond the original decision, particularly in cases where the claimant has already received a reduced award, fearful of losing entitlement to the benefit altogether on appeal[1161].

Universal Credit Cuts to Disability Benefits

Since the introduction of Universal Credit, d/Deaf and disabled people considered to have limited capability for work within Universal Credit and Employment Support Allowance but deemed capable under the work capability assessment to undertake work related preparation activities, have lost entitlement to a disability premium of £128 per month (£29.05 per week)[1162].

[1161] Disability Action Caseload 2020.

[1162] DfC (2016): Northern Ireland Universal Credit Information Booklet, p.32.

Since the onset of the Covid-19 pandemic, claimants in receipt of Universal Credit received an additional £20 per week[1163]. This increase was not applied to claimants, including d/Deaf and disabled people, on legacy benefits such as Income Support and Jobs Seekers Allowance, an issue that is currently the subject of legal action[1164]. The £20 additional payment through Universal Credit was removed on 6 October 2021[1165]. This is likely to have a significant impact on over 26,010 households which include adults and children with disabilities on Universal Credit[1166].

[1163] DfC (2021): Minister Hargey urges DWP to retain £20 Universal Credit uplift (accessed 5 November 2021).

[1164] Osbornes/Law (29 April 2021): High Court challenge the denial of benefit increases for nearly 2 million people with disabilities. The high court is to decide whether it was lawful for the government not to give people with disabilities social security benefits the same £1040 a year increase that it has given to all recipients in receipt of universal credit.

[1165] The Conversation (2021): Universal credit uplift was a lifeline during the pandemic – our research shows cutting it will leave families with impossible decisions (accessed 5 November 2021).

[1166] Within Universal Credit there are currently 26,010 households with a working age adult with a disability in receipt of Universal Credit payments that include additional elements of Limited Work Capability and Limited Work Capability work related activity. Both these groups comprise of disabled people and those with long-term health conditions. Those disabled people in the Limited Work Capability receive no additional financial support and are not required to search for employment but must undertake work related activities such as preparing CV's and undertaking training courses while those d/Deaf and disabled people in the limited capability for work and limited capability for work related activities do not have to look for work and receive an additional social security benefit of £343 per month. A further 4,270 households that include a d/Deaf and disabled child are also in receipt of Universal Credit. Department for Communities (May 2021): NI Universal Credit Supplementary Statistics Tables, See Tables 8a, b and c, Households in Payments with Additional Elements October 2017 – May 2021.

Working claimants in receipt of Universal Credit, including d/Deaf and disabled claimants, have been compensated through a reduction the taper rate from 63p to 55p in the October budget[1167], allowing people on Universal Credit to earn extra money, approximately £1,000 per annum[1168]. However, unemployed people in receipt of Universal Credit are not eligible for any additional money.

In June 2018, the High Court found that the implementation of Universal Credit unlawfully discriminated against two severely d/Deaf and disabled men whose benefits were dramatically reduced when they were required to migrate to Universal Credit after moving to a different local authority area[1169]. Prior to moving to Universal Credit both men were in receipt of the Severe Disability Premium (SDP) and enhanced disability premium (EDP) which are aimed at meeting the additional needs of severely disabled people who live alone.

[1167] HM Treasury (2021): Autumn Budget and Spending Review 2021: Policy Costings (accessed 5 November 2021).

[1168] The Guardian (2021): Budget 2021: Sunak softens universal credit cuts to tackle squeeze on families (accessed 5 November 2021).

[1169] R (TP and AR) v Secretary of State for Work and Pensions (Universal Credit) [2018] EWHC 1474 (Admin).

The High Court found that the implementation arrangements for Universal Credit were contrary to Article 14 of the ECHR in conjunction with Article 1, Protocol 1. The Equality and Human Rights Commission (EHRC) intervened in the case arguing that Article 14 of the ECHR, when read with the UNCRPD, imposes positive obligations of the UK to address and remove the obstacles faced by d/Deaf and disabled people in enjoying equal rights. In response DWP committed to introducing changes to ensure that no severely disabled person in receipt of the SDP will be required to move onto Universal Credit without transitional protection in place and to compensate those who have lost out[1170].

It is important to note that Transitional Protection Payments went live in February 2021 when the SDP ended. These payments will only compensate for the loss of a SDP and are only available to people who have received SDP within their Income Support, Job Seekers Allowance (JSA) or Employment Support Allowance (ESA) in the month before they claim Universal Credit and continue to meet the eligibility conditions for SDP.

[1170] UK Parliament (2018): Universal Credit: written statement – HCWS745, 7 June 2018 (accessed 4 November 2021).

The Transitional Protection Payment amounts to £120 per month which is much lower than SDP. Furthermore, Transitional Protection is not available to people who are only receiving SDP within their Housing Benefit or to people claiming benefits for the first time.

There were 528,000 working-age households in receipt of SDP within their legacy benefits in 2017-18. The vast majority were in receipt of ESA[1171]. Since 2017-18 households are required to claim Universal Credit even if they would have previously met the conditions for SDP. The Transitional element of Universal Credit only compensates for the loss of SDP.

Many in receipt of Enhanced Disability Premium have transitioned to Universal Credit, receive less money and are not eligible for Transitional Protection. It is also important to note that Transitional Protection will decrease over time with the overall objective that no households will receive protection at some point in the future.

[1171] Northern Ireland Executive (2016): 'Welfare Reform Mitigations Working Group report' (accessed 27 March 2022).

Health and Disability Green Paper

In August 2021, the UK Government[1172] consulted on a Health and Disability Green Paper regarding options for addressing some of the short-to medium-term issues in health and disability benefits and identifying opportunities for wider change to the health and disability benefit system. The Green Paper[1173] sets out the philosophy that has underpinned the Government's welfare reform programme over the last 15 years that:

- employment is the way out of poverty;[1174]
- the need for reduction in spending on social security benefits for d/Deaf and disabled people[1175] including the demarcation of a new severe disability group, likely to lead to further reductions in social security for many d/Deaf and disabled people[1176].

There is a strong emphasis in the Green Paper on people with mental health issues, highlighting the level of support provided by the Government in terms of employment support but also repeatedly pointing out that people with mental health issues make up over 50% of claims to PIP.

[1172] Department for Work and Pensions (2021): Shaping future support: the health and disability green paper (accessed 5 November 2021).
[1173] Ibid.
[1174] Ibid, Executive Summary.
[1175] Ibid, paragraph 310.
[1176] Ibid, paragraph 207.

The Department for Communities highlights that 42% of PIP claimants cite mental health issues as the main reason for applying for the benefit[1177]. It was also of note that the Secretary of State for Social Security in the UK, in a 2021 press conference, made repeated references to the need to cut spending on disability benefits, highlighting that 3 out of 4 young people who claim PIP state that their primary reasons for claiming the benefit is their mental health[1178].

DPOs in NI and GB view the government's proposals as part of an agenda to reduce costs and a further retrogression of the right of d/Deaf and disabled people to adequate financial support[1179].

[1177] Department for Communities (2021) Personal Independence Payment Experimental Statistics, pp 1-5 (accessed 31 December 2021).

[1178] Disability News Service (2021): Conservative conference: Coffey says merging PIP with universal credit is 'on the table' (accessed 31 December 2021). Conservative Party Conference, response from Secretary of State to the question from the Disability News Service as to whether or not the government intended to combine the Personal Independence Payment with Universal Credit. The Secretary of State refused to rule out the possibility of combining both benefits. This would likely have adverse financial implications for d/Deaf and disabled people currently in receipt of both these benefits. The disability and sickness element of universal credit of £343 per month could possibly be reduced on the grounds that current recipients of PIP are already in receipt of a maximum of £605 if they meet the enhanced rates of daily living and mobility components. At present d/Deaf and disabled people can claim to have met the threshold requirement of both benefits through both the PIP and work capability assessments can claim both but the integration of both benefits could lead to an overall reduction in the amount of social security that d/Deaf and disabled people receive.

[1179] Disability Rights UK (2021): Health and Disability Green Paper – a cause for concern (accessed 2 January 2021).

Sanctions

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 that a Freedom of Information response regarding sanctions or 'adverse decisions' relating to people accessing Employment and Support Allowance (ESA), showed that 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. d/Deaf and disabled people have asked for these sanctions to stop[1180]. Sanctions exacerbate the existing illnesses and impairments of d/Deaf and disabled people with particularly negative impacts upon those with mental health conditions[1181].

[1180] PPR (2018): Right to Work: Right to Welfare Group, Cruelty: Social Security, the Economy and Human Rights (accessed 2 January 2022).

[1181] Dwyer, P., Jones, K., McNeill, J., Scullion, L. and Stewart, A. (2018): Final findings: deaf and disabled people (accessed 3 November 2021).

The Scottish Human Rights Model of Social Security

The Scottish Government has utilised the opportunities of devolution to take a different approach to social security. The overall intention was to eradicate the adversarial nature of system, replacing it with a new, distinctly Scottish system founded on dignity, respect, and human rights. The Scottish social security adopts the following approach:

- 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;
- Scottish Ministers have a role in ensuring that individuals are given what they are eligible to be given under the Scottish social security system;
- opportunities are to be sought to continuously improve the Scottish social security system in ways which put the needs of those who require assistance first;
- the Scottish social security system is to be efficient and deliver value for money.

The Scottish system seeks to reverse the stigma currently associated with accessing assistance and will seek to support and encourage people to exercise their rights to the fullest possible extent. This is reflected in the principle that 'Social security is itself a human right, essential to the realisation of other human rights' [1182].

The Disability Strategy has recommended that the Scottish approach is implemented in the region[1183].

The Disability Strategy Expert Advisory Panel have proposed the following recommendations:

- 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 d/Deaf and disabled people into employment that does not conflict with their right to an adequate standard of living and entitlement to social security;

[1182] Scottish Government (2017): Social Security principles and a rights based approach (accessed 3 February 2022).

[1183] DfC (2020): Disability Strategy Expert Advisory Panel Report, page 46 (accessed 18 December 2021).

- 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 UNCRPD obligations. The Northern Ireland Government must reflect this human rights approach, which 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; Council of Europe’s Committee of Social Rights;

- research to consider the impact of welfare reforms on specific disability grounds e.g., for example mental health issues or upon 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 mitigation measure of a £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;
- 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 disabled people on low income in particular for those 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 considers the additional costs to childcare providers of caring for a disabled child;
- remove the two-child limit;
- provide support for disabled people to access appeals and complaints mechanisms related to social security entitlements and enforce remedies for any breach of entitlements[1184].

[1184] DfC (2020): Disability Strategy Expert Advisory Panel Report, pp.46-48.

Article 29: Participation in Political and Public Life

> "*Disabled people are underrepresented in employment and positions of influence. Real and ambitious opportunities for disabled people within positions of responsibility and influence is needed to fully realise a society that is equitable for disabled people".*
>
> **Disabled woman carer with a health condition, aged 40-44.**

Article 29 requires that State Parties guarantee d/Deaf and disabled people political rights and the opportunity to enjoy them on an equal basis with others. State Parties should:

- ensure that disabled people can effectively participate in public life on an equal basis with others, directly or through freely chosen representatives including the right to vote and be elected by:
    1. ensuring that voting procedures, facilities and materials are appropriate, accessible, and easy to use;
    2. protecting the right of disabled people to vote by secret ballots in elections and referendums with intimidation, to stand for election, to effectively hold office and perform at all levels of government and facilitating the use of assistive and new technologies;

- guaranteeing the free expression of the will of disabled people as electors and on request allowing assistance with voting of their own choice;
- Actively promoting an environment in which d/Deaf and disabled people can effectively and fully participate in the conduct of public affairs without discrimination and on an equal basis with others, and encourage their participation in public affairs including:
    1. participation in non-governmental organisations and associations concerned with public and political life and in the active administration of political parties;
    2. forming and joining DPOs at international, national, regional, and local levels[1185].

The UNCRPD Committee has highlighted the importance of the right to participate in political and public life in its General Comment No. 7: ‘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.

[1185] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, (Article 29) (accessed 4 November 2021).

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'[1186].

The Committee raised concerns regarding insufficient information with respect to accessibility and reasonable accommodation for people with disabilities at all stages of the electoral life cycle aimed at facilitating the right to vote, to vote in private, and choice with respect to assistance. The Committee was also concerned at the low numbers of people with disabilities who hold or run for public office.

The Committee recommended that the State Party work with DPOs to take appropriate measures to secure accessibility for d/Deaf and disabled people regardless of disability and to repeal provisions which restrict the right of persons with disabilities to vote and ensure the provision of reasonable accommodation to guarantee the possibility and right to universal and secret suffrage[1187].

[1186] UN 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, (CRPD/GC/7), paragraph 88.

[1187] 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, CRPD/C/GBR/CO/, paragraph 60 (accessed 4 November 2021).

d/Deaf and disabled people are underrepresented in political and public life in Northern Ireland[1188]. Participants within the qualitative research to inform this report were vocal regarding their under-representation but noted the NI Assembly's Disabled Person's Parliament as a positive development. The Equality Commission has raised concerns regarding the barriers that d/Deaf and disabled people face with respect to registration to vote and exercising voting rights[1189]. The participation of d/Deaf and disabled people in public life is a strategic commitment of the NI Executive but not it is no clear how this is to be achieved in practice[1190].

Participants in the qualitative research informing this report told us they felt they had limited access to decision-making and that including d/Deaf and disabled people in decision making would enhance equality:

[1188] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, p.109 (accessed 10 October 2021).

[1189] ECNI (2019): Equality in Participation in Public Life, paragraphs 7.1-7.7, pp.26-27 (accessed 5 November 2021).

[1190] The Executive Office (2011): Public Bodies and Public Appointments Annual Report 2009/2010, p.30 (accessed 5 November 2021).

> “*Disabled people are not at the table. They are not part of policy making. We seem an afterthought. Disability isn’t a wheelchair - disability is a huge spectrum of people living with a range of conditions who need to be included in all of society - not just accommodated.*”
>
> **Disabled woman, carer and a representative of a DPO, aged 40-44.**

Measures to encourage the participation of d/Deaf and disabled people in public life have been ineffective in addressing underrepresentation[1191]. Whilst there is a Guaranteed Interview Scheme for public appointments in place this has not significantly increased representation on public bodies significantly[1192].

In 2008/2009 only 3% of public appointments were from applicants known to be disabled people[1193]. However, 25% of the Northern Ireland population aged 18 years and over have a long-term health issue or disability[1194].

[1191] Ibid, paragraph 5.11, p.13.

[1192] Ibid, paragraph 5.3, p.11.

[1193] The Executive Office (2011): Public Bodies and Public Appointments Annual Report 2017/18, p.30 (accessed 5 November 2021).

[1194] Ibid, paragraph 1.5, p.12.

The latest published figures for public appointments in 2017/2018 demonstrate little improvement with a 4% appointment rate despite a 2% increase in application rates from d/Deaf and disabled people[1195].

In 2007, as a result of lobbying and effective engagement from the Equality Commission, the disability equality legalisation was amended in Northern Ireland to introduce a public sector disability duty. This duty placed a requirement on all public authorities to promote positive attitudes towards disabled people and their participation in public life[1196]. The Executive Office's[1197] Disability Action Plan (DAP) 2020-2025 contains no specific measures to promote the participation of disabled people in public life and contains no quantifiable outcome focused measures to respond to either duty to promote positive attitudes or public life[1198]. The plan refers to the ratification of the UNCRPD in 2009, highlighting the Department's sponsoring role with regard to the Equality Commission[1199].

[1195] NISRA (2020): Public Appointments: Annual Report for Northern Ireland 2017-2018, paragraphs 2.4 and 3.5, pages 16 and 20 (accessed 15 October 2021).

[1196] ECNI (March 2007): A Guide to Public Authorities: Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life. Public Authorities are required to develop a Disability Action Plan setting out measures how they will promote positive attitudes towards disabled people and encourage their participation in public life.

[1197] The Executive Office is the lead Department for Public Appointments.

[1198] The Executive Office (2020): Disability Action Plan 2020-2025, paragraph 63, p.22.

[1199] Ibid.

An assessment of all Government Departments' current disability action plans, including that of the Northern Ireland Office, undertaken to inform this report, shows that all but one Government Department developed an appropriate, unambitious commitment, to encourage d/Deaf and disabled people into public life[1200]. None of the Government Departments have taken the opportunity to consider dual measures to promote positive attitudes towards disabled people and encourage their participation in public life through any of the disability awareness training measures that they are required to commit to in every action plan.
All departments have failed to engage directly with d/Deaf and disabled people or their representative organisations to provide disability equality training[1201], despite ongoing advice from the Equality Commission and DPOs.

[1200] The Executive Office (April 2021): Disability Action Plan 2021-2026, page 30, commits to two job shadowing opportunities for disabled people in a five year plan (accessed 2 January 2022).

[1201] Disability Equality Training is training provided by disabled people through expertise gained from lived experience. Only three public authorities have directly engaged with disabled person's led organisations to deliver training measures set out within the disability action plans. In the last five years, no government department has considered action measures in this regard. There is a tendency to rely exclusively on disability awareness training with strong emphasis on online training rather than promoting public life opportunities by engaging directly with disabled people and their representative organisations.

Only one Government Department committed to delivering public life positions/opportunities for d/Deaf and disabled people but sets a rather low standard committing only to ensuring two d/Deaf and disabled people to be directly involved in a job shadowing scheme[1202]. It should be noted within this legislation that the definition of public life is extremely broad and flexible, and this was noted by one Government Department which highlighted correctly that public life is much wider than public appointments, and can include, for example, participation on working groups, teams, forums, selection panels and user groups provided by government.

Positively, the same Government Department sets out a measure to encourage participation in a disability forum to involved d/Deaf and disabled people but such direct measures were not in evidence across Government Departments and in this case no targets were set, or timeframe established to achieve a particular outcome. Several government departments have not even considered, in any shape or form, public life measures within their action plans[1203].

[1202] The Executive Office (April 2021): Disability Action Plan 2021-2026, at page 30, commits to two job shadowing opportunities for disabled people in a five year plan (accessed 2 January 2022).

[1203] For example, the Department of Health, the Department of Justice and the Northern Ireland Office disability action plans contained no measures to promote the participation of disabled people in public life.. The only public life measure considered in the Department of Health (April 2019) Disability Action Plan 2019-2024

Public life measures tend to be processed based focussed on outputs rather than genuine concrete consideration of promoting public life positions and public life opportunities for d/Deaf and disabled people. Significantly, a key failing in this area is lack of enforcement arrangements in relation to the disability duties. The Equality Commission has no powers, effective or otherwise, to enforce government departments or public authorities more generally to comply with either the spirit or the intent of the legislation. Public authorities are only required to give 'due regard' to take account of the disability duties rather than the stronger compliance requirements associated with disability discrimination legislation (the DDA), such as the reasonable adjustment duty in relation to employment or goods, facilities, and services.

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is an action to ensure that the voices of carers are heard through the public health agencies '10,000 More Voices Initiative' (it should be noted whilst the Department is promoting public life opportunities for d/Deaf and disabled people through the Regional Disabled People's Health Forum and the Autism Interim Strategy, none of these measures are highlighted in the action plan).
The Department of Justice (September 2016) Disability Action Plan 2017-2022 claims it will identify and encourage participation of disabled people in public life in career development and management support for disabled staff and candidates but does not include any quantifiable indicators or targets.

The only formal evaluation of public authorities' performance in relation to the disability duties (2009), highlighted a degree of cynicism among d/Deaf and disabled stakeholders suggesting that there was little evidence of any difference made; partly based on the low response rate from d/Deaf and disabled people and their representative organisations to consultations on action plans[1204].

Some DPOs are no longer engaging with public authorities in the development of their disability action plans because of what they consider to be the general poor standards of these plans[1205]. Indeed, in one government department's action plan assessed for this report, a consultation on their action plan held late in 2019, received no responses from d/Deaf and disabled people, or organisations representing their interests[1206]. One Government Department's action plan, assessed for this report, held a consultation on their plan (2019) but received no responses from d/Deaf and disabled people, or organisations representing their interests[1207].

[1204] ECNI (2009): Evaluating the Effectiveness of the Disability Discrimination Northern Ireland Order 2006 Duties Research Report Findings, para 1, page 11.

[1205] DPOs such as Omnibus, Centre for Independent Living and the Northwest Forum of People with Disabilities, no longer respond to disability action plans due to their lack of quality, available resources and other priorities (Northern Ireland DPO monthly meetings since March 2020).

[1206] Department of Education (January 2021): Disability Action Plan 2020-2024, paragraph 1.6, page 3 (accessed 2 January 2022).

[1207] Department of Education (2021): Disability Action Plan 2020-2024, paragraph 1.6, page 3 (accessed 5 November 2021).

The UK Electoral Office has identified barriers to elected office as including attitudinal perceptions; caring responsibilities; financial costs; institutional norms; political culture; time constraints; lack of support networks; and levels of political experience[1208].

Participants in the research to inform this report referred to physical barriers in exercising their vote, challenges in accessing postal votes due to the wiping of the register, and the lack of adjustments for d/Deaf and disabled people in exercising their vote. People with visual impairments can access information regarding where to put the X on the ballot but cannot determine the candidates to which the X relates to:

> "*From the point of view of a visually impaired voter, templates provided for polls are not individually designed and therefore only half useful. That indicates merely where to X the box and not for whom you are selecting.*"
>
> **Disabled man, aged 50-54.**

[1208] UK Government Equalities Office (2021): Barriers to elected office for disabled people (accessed 5 November 2021).

Political Parties in the UK have broadly acknowledged these barriers and, to various degrees, sought to put in place strategies for helping address the under-representation of particular social groups, although their efforts have predominantly targeted women and ethnic minorities[1209].

Participants in the qualitative research informing this report have told us of their aspirations to participate in politics and their doubts about being taken seriously:

> *“I would love to be involved in politics but don't know how to get involved. I don't feel I would be accepted or taken seriously enough - sometimes it feels like it is a talking shop - nothing changes. It feels like it is just a tick box exercise.”*
>
> **Disabled Carer with a long-term health condition**

Although funds had been made available to compensate d/Deaf and disabled candidates in Great Britain for disability related costs during political campaigns through the Access to Elected Office Fund[1210], the fund was closed in 2018[1211].

[1209] Ibid.

[1210] Waltz, M. and Schippers, A. (2021): Politically disabled: barriers and facilitating factors affecting people with disabilities in political life within the European Union, Disability & Society, 36:4, pp. 517-540.

[1211] Disability Rights News Service (2020): Government blames coronavirus crisis for closure of elected office fund (accessed 5 November 2020).

The closure had an adverse impact on d/Deaf and disabled people running for elected office. For example, in one instance a blind candidate had to depend on family and friends for support in relation to door-to-door canvassing during a national election because there was no funding available for a personal assistant[1212]. Following a campaign by cross-party political organisation, the Fund was subsequently reopened, for local government candidates only, in England at the end of 2018, in advance of the 2019 election (for a duration of 12 months)[1213]. No such fund was available to any perspective d/Deaf and disabled candidates running for public office in Northern Ireland and there are no plans to introduce such a fund.

[1212] Waltz, M. and Schippers, A. (2021): Politically disabled: barriers and facilitating factors affecting people with disabilities in political life within the European Union, Disability & Society, 36:4, pp 517-540.

[1213] Ibid.

Participants in the qualitative research to inform this report told us that whilst they wished to participate in decision making, they were turned off by voting:

> *“We lack representatives from our community in the government and no one who is in government - mostly nondisabled - care for our issues or lives as people. I don’t vote as I have yet to be given a reason to do so, no one in government represents me or my issues, many venues are also inaccessible when voting as I have heard from fellow disabled friends.”*
>
> **Disabled man care with a health, aged 16-24**.

The inaugural Disabled People’s Parliament was held in the decision-making chamber of the NI Assembly on International Day for People with a Disability - Friday 3 December 2021. Speaking in reflection on the Parliament, participants in the qualitative research welcomed the initiative:

> “*As far as I can see there is very little positive action taken to encourage disabled people to participate in politics. That said, the Disabled People's Parliament was an extremely positive development - hopefully it will become an annual event.”*
>
> **Disabled man with a long-term health condition, aged 50-55.**

The Parliament was the first ever to be held in the UK[1214]. The event was hosted by the Speaker, Alex Maskey MLA, in the Assembly Chamber in Parliament Buildings. This initiative was organised in partnership with Disability Action and a range of disability rights groups and organisations. The Parliament brought together d/Deaf and disabled people from across the region to debate a collective motion calling on the Northern Ireland Executive and Assembly to incorporate the UNCRPD into the laws of Northern Ireland, one the key recommendations of the UNCRPD Committee.

Fourteen speakers presented their perspectives and experiences as both activists and d/Deaf and disabled people, on why a change to the law based on the UNCPRD is essential to secure proper legal supports, rights, and equality for themselves, and all d/Deaf and disabled people. Participants in the debate used evidence and drew on personal experience to highlight the importance of incorporating the convention and outlining what difference it will make to their lives. Participants included a mother advocating on behalf of her young daughter.

Each participant shared their view on why the UNCRPD was important to them, referencing many specific rights within the Convention, including the rights:

[1214] NI Assembly (2021): Speaker hosts first Disabled People's Parliament (accessed 3 January 2022).

- to dignity;
- to make decisions and influence government;
- to equality and non-discrimination particularly in light of Brexit and loss of future protection provided by the European Union;
- to accessible housing, play parks, changing places for our children, transport goods services and information;
- to health, employment and education, including the rights of children and young people with visual impairments; for disabled people not to be seen a cheap labour; and the importance of genuine employment opportunities;
- to life, particularly in the context of experiences of covid 19, including the fact that two thirds of disabled people have died as a result of the pandemic;
- to access justice, the support of policing services and the courts;
- to non-degrading and inhuman treatment highlighting the experience of people in Muckamore in challenging institutional discrimination and the demand for the right to independent living and greater investment in supporting the right to live in the community on an equal basis with others;

- the right to life, including calling on political leaders to end the practice of ‘do not resuscitate’ orders, regarded by many as imposing a death sentence against the will of disabled people;
- d/Deaf and disabled people highlighted that human rights are not negotiable and should not be subject to a price tag.

During the debate:

- Amanda Paul told how she suddenly became disabled as a married adult and was confronted with a world of previously unknown challenges and outlined particular challenges she had experienced with respect to her Right to Life;
- Christine McClements joined the chamber virtually with her disabled daughter Lilia. Christine and Lilia passionately asserted Lilia’s right to equality and outlined the exclusion which she faces every day of her life;
- Disability Rights activists Dermot Devlin and Michaela Holywood clearly explained that employment rights for people with disabilities and legislation for UNCPRD were needed just to create a level playing field;
- both Michael Johnston and Joe Kenny described managing their respective lives and vocations with hearing and sight loss;

- the impact of Multiple Sclerosis, stress, and panic attacks in her life were outlined by Greta Gurklyte. She stated that the right of access to health care should not be about luck or coincidence;
- the need for reliable, disability accessible public transport; investment in community care, and respect for people with learning disabilities was clearly explained by Alison Lockhart, Ronnie Patterson and Jackie Robins;
- both Diane Marks and Rosie Dempsey addressed the challenges faced by adults, and children in school who live with complete or partial loss of sight.

Declan Kearney MLA, Junior Equality Minister in The Executive Office, responded to the debate by committing to the incorporation of the UNCRPD into law, although noting the need for cross-departmental support[1215]:

> "*Rights delayed are rights denied. There should be no legislative impediment and there should be no price tag attached to how we secure the human rights of disabled people. Together we will ensure the human rights of disabled people will be enshrined and protected.*"

[1215] NI Assembly (2021): Disabled People's Parliament (accessed 30 December 2021).

There has been no formal engagement by the State party with d/Deaf and disabled people and the wider disability sector as to the potential impact of Brexit, including the recent introduction of the Northern Ireland protocol. However, in May 2021 the Northern Ireland Civic Working Group on the Protocol (NICWGP)[1216] was established in recognition of the significant impact that Brexit and the Northern Ireland Protocol has had and will likely continue to have on Northern Ireland.

Through the working group, Disability Action and the Northwest Forum of People with Disabilities met with EU negotiator Maros Sefcovic and UK negotiator Lord Frost, to raise concerns regarding the protection and promotion of the rights of d/Deaf and disabled people, including access to medicine and the negative impact of the ongoing instability associated with Brexit.

There are elements of good practice, regarding participation of disabled people in public life, in the development of the proposed Disability Strategy, evident through the composition of the Expert Advisory Panel - 3 of 4 appointed experts were d/Deaf and disabled people[1217].

[1216] The NICWGP is chaired by Professor Katie Hayward, Professor of Political Sociology, Queens University Belfast, and Senior Fellow of the UK in a Changing Europe Think Tank. Professor Hayward is an internationally recognised expert on Brexit and Northern Ireland, she was appointed to the Technical Expert Panel of the UK Governments Alternative Arrangements Advisory Group on Brexit (2019).

[1217] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations (accessed 10 October 2021).

The Co-design Group includes representative of DPOs[1218]. More recently there have been concerns regarding the progress of the strategy, which are largely associated with barriers associated with cross-departmental working. In response to concerns, Minister Hargey met with the Co-design Group in January 2022 to hear representations regarding the content of the strategy.

The illustrative human rights indicator for Article 29[1219] requires verification of concrete activities undertaken by public authorities to involve persons with disabilities in decision-making processes related to issues that directly or indirectly affect them (in line with Article 4.3 of the UNCRPD and general comment no. 7 of the UNCRPD Committee). Such activities include consultation meetings; technical briefings; online consultation surveys; and calls for comments on draft legislation and policies.

[1218] DfC (ND): Disability Strategy co-design group - terms of reference (accessed 2 January 2022).

[1219] United Nation Office of the High Commissioner for Human Rights (2020): Article 29: List of illustrative indicators on participation in political and public life (accessed 5 November 2021).

The Disability Strategy Expert Advisory Panel has proposed the following recommendations:

- 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;
- 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 and service to the community should be taken into account[1220].

The authors of this report propose the following recommendations:

- training activities should be delivered to organisations of persons with disabilities to strengthen their capacity to participate in all phases of policymaking and in political and public life;
- financial support should be allocated to DPOs to strengthen their capacity to participate in public decision-making processes;

[1220] DfC (2020): Disability Strategy Expert Advisory Panel: Report and Recommendations, pp.104-105 (accessed 10 October 2021).

- consultation processes should be undertaken to ensure active involvement of d/Deaf and disabled pep[le, including through their organisations, in the design, implementation and monitoring of laws, regulations, policies and programmes, related to the right to vote, be elected, hold office, and perform public functions[1221].

[1221] United Nation Office of the High Commissioner for Human Rights (2020): Article 29: List of illustrative indicators on participation in political and public life (accessed 5 November 2021).

Article 30: Participation in cultural life, recreation, leisure, and sport

> "*Not one bit, the guilt I feel when I treat myself to the cinema or a takeout never goes away. Non-disabled people can spend in most cases without guilt (except for those affected by poverty), yet my existence is a constant checklist of what do I need how much is it etc. I'd love to own a sports wheelchair to get exercise alongside my brother, I'd love him to have his own so we could play basketball or tennis etc. Yet I can't even think of buying a chair as a decent one is almost £1500 to £2000. I have dreams that may never be reality due to being disabled".*
>
> **Disabled man with a long-term health condition, aged 16-24.**

Article 30[1222] requires State parties to recognise the right of d/Deaf and disabled people to take part on an equal basis with others in cultural life, and to take measures to ensure that d/Deaf and disabled people:

- enjoy access to cultural materials in accessible formats;
- enjoy access to television programmes, films, theatre, and other cultural activities, in accessible formats;

[1222] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, (Article 29).

- enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries, and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.

State parties are required to take:

- appropriate measures to enable d/Deaf and disabled people to have the opportunity to develop and utilize their creative, artistic, and intellectual potential, not only for their own benefit, but also for the enrichment of society;
- all appropriate steps to ensure that laws protecting intellectual property rights do not constitute unreasonable or discriminatory barriers to access to cultural materials by d/Deaf and disabled people;
- recognises that d/Deaf and disabled people are entitled on an equal basis with others to the recognition and support of their specific cultural and linguistic identity including sign language and deaf culture.

State parties are also required to:

- encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;

- ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training, and resources;
- ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure, and sporting activities.

Obligations under Article 30(5) of the Convention include the rights of d/Deaf and disabled people to participate in recreation, leisure, and sports on an equal basis with others, including mainstream and disability-specific sporting activities, recreational, leisure and tourism venues, and in education.

The Article contains guidance on a human rights-based approach to develop inclusive and disability-specific physical activity and sports and recommendations to assist States in implementing their obligations[1223].

The UNCRPD Committee is concerned that the NI Executive and the UK Government has not ratified the Marrakesh Treaty to Facilitate Access to Published Works for Persons who are Blind, Visually Impaired, or Otherwise Print Disabled. The Committee raised concerns about the low level of accessibility to sports stadiums with individual seating for persons with disabilities and their families, friends, and personal assistants, and to national heritage sites, including those appointed as United Nations Educational, Scientific and Cultural Organization (UNESCO) heritage sites.

The Committee recommended that the NI Executive and UK Government:

- take all necessary steps to ratify and implement the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled as soon as possible;

[1223] OHCHR (2021): Report on physical activity and sports under article 30 of the Convention on the Rights of Persons with Disabilities (accessed 22 December 2021).

- adopt a concrete plan of action, with resources and measurable objectives, to implement legislation, regulation, and standardization to ensure that persons with disabilities have access to inclusive participation in all sports facilities and heritage sites, including UNESCO heritage sites[1224].

d/Deaf and disabled people face several barriers to engaging in physical activity and sports, including inaccessible physical environments, attitudinal barriers, the lack of suitable equipment, support, disability-specific knowledge, accessible information, and the likelihood of extra costs.

In addition, there are far fewer resources allocated to promote inclusive and disability-specific sports, recreation, and leisure. As a result, persons with disabilities are more likely to be physically inactive and have poorer health outcomes and greater health inequalities[1225].

[1224] 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, CRPD/C/GBR/CO/1, paragraphs 62-63 (accessed 4 November 2021).

[1225] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, (Article 30) (accessed 4 November 2021).

Over the years, there has been growing attention to the role of sports in promoting social inclusion and human rights for all members of society, including persons with disabilities. Article 30(5) of the Convention explicitly recognises the right of persons with disabilities to participate in physical activity and sports on an equal basis with others and calls on States to enable their participation, including by protecting against discrimination and dismantling structural inequalities in access and funding, to ensure the inclusion of children with disabilities and women and girls with disabilities[1226].

Article 30(5) of the Convention addresses both mainstream and disability-specific sports, encompassing sports competitions, physical activity in education, and recreation and leisure. Persons with disabilities have rights, both as participants engaging in physical activities and sports, as well as in the role of spectators, consumers, or organisers of activities. More widely, States have the obligation to actively involve persons with disabilities and their representative organizations in decision-making relevant to sports and physical activity[1227].

In order to meet the obligations under article 30(5), States should undertake steps to:

[1226] Ibid.

[1227] Ibid.

- review legislation and regulations to ensure non-discrimination, equal access and equitable funding distribution for inclusive and disability-specific sports;
- invest in accessible infrastructure including through procurement policies;
- ensure the availability of assistive technologies and support, including grants to engage in inclusive and disability-specific sports, fostering cross-movement collaboration between athletes with disabilities and the larger community of athletes;
- promote awareness-raising, research and data collection for more effective and tailored measures to increase engagement by persons with disabilities in physical activity and sport, particularly by women and girls with disabilities; and promote technical cooperation and exchange through international cooperation[1228].

While advances are being made globally for the inclusion of persons with disabilities in sport and physical activity, further efforts are needed to strengthen enforcement and accountability mechanisms to monitor resource allocation and track progress.

[1228] Ibid.

In addition, States have a duty to regulate private actors to ensure non-discrimination against persons with disabilities and enable access to physical activity and sports; States should work with the private sector to support the development of inclusive practices[1229].

d/Deaf and disabled people in NI have the lowest sport participation rates compared with other jurisdictions in the UK and Ireland at 28% compared to Wales which is the highest at 38%[1230]. Comparing participation levels between 2010 and 2020, people with disabilities in Northern Ireland (NI) are still almost half as likely to regularly participate in sport and physical activity as non-disabled people[1231].

According to Disability Sport NI, access to sport facilities has improved in response to legislation. Since 2014, twenty facilities have been awarded DSNI's Inclusive Sports Facility Accreditation Scheme, 10 NI Governing Bodies have an Inclusive Sport Award, and all 11 District Councils have a 'Disability Sport Hub'[1232].

[1229] Ibid.

[1230] RAISE (2021) Sport and disability in Northern Ireland, Table 2, p.22 (accessed 22 December 2021).

[1231] Ibid. p.1.

[1232] Ibid, p.20.

An investment of up to £1.1 million was budgeted to establish 11 multi-sports facilities for d/Deaf and disabled people in each of the Council areas and provide specialist equipment for these venues[1233]. Despite this investment, the Continuous Household Survey demonstrates that the gap between disabled and non-disabled members of sports clubs is widening[1234].

The 2019 Sport NI Club survey[1235] reported that 3% of 128,587 club members were people with disabilities. Club access for people with disabilities was noted as a barrier by 12% of sports clubs with outdoor facilities and 7% with indoor facilities.

In 2016, the 'Active Living – No Limits 2016-2021'[1236] strategy was published. This provided a co-designed framework for £1.1million of investment and a strategic project board to oversee the achievement of the 17 actions identified, following consultations with people who have disabilities and their carers. The vision of the plan was to encourage a collaborative approach to increasing sport and active recreation by d/Deaf and disabled people[1237].

[1233] Ibid, p. 22.

[1234] Ibid, p.20.

[1235] Sport NI (2019): Sport Club Survey 2019 (accessed 22 December 2021).

[1236] Sport NI (ND): Active Living: No Limits 2021 (accessed 23 December 2021).

[1237] Sport NI (ND): Active Living: No Limits 2021, p.2 (accessed 23 December 2021).

The purpose of the Action Plan is to:

- give direction to the development of disability sport across Northern Ireland;
- encourage strategic and joined up working;
- agree where the sector would like to be by 2021 and provide a guide for how to get there;
- provide a framework for strategic investment in disability sport.

During the consultation for the Action Plan, a deficit in local, inclusive, and accessible sport and active recreation opportunities was identified[1238]. The need for people with a disability to be trained and employed as coaches and to advise on project development was identified as a priority[1239]. The plan prioritised five outcomes:

Engage and Encourage

- people with a disability are supported by a strong, well-coordinated disability sport sector;
- people with a disability have positive experiences because of changed public attitudes and a greater understanding of disability.

[1238] Ibid, p.9.

[1239] Ibid, p.10.

Active and Inclusive

- people with a disability lead active lifestyles and have improved health and wellbeing through involvement in sport and active;
- recreation; people with a disability have equality of choice and consistency of accessible activities and sporting facilities.

Involved and Inspired

- people with a disability face 'No Limits' in sport and active recreation[1240].

The Action Plan committed to establishing:

- a Cross-Departmental Disability Sport Forum - to create links and enable a networking and information sharing platform between relevant government departments, agencies, etc. and organisations within the disability and sports sectors;
- a Northern Ireland Active Living: No Limits Forum - to support the delivery, monitoring and realisation of the outcomes of this Action Plan[1241].

[1240] Ibid, p.11.

[1241] Ibid, p.12.

Since 2014, activities to develop disability sport provisions include:

- publication of an Active Living No Limits Strategy 2016 – 2021[1242];
- a 'Disability Sport Hub' in all 11 District Councils[1243];
- an Inclusive Sport Award achieved by 8 NI Sport Governing Bodies[1244];
- improved wheelchair basketball and boccia programmes[1245];
- Inclusive Sport Facility Accreditation for 18 sports facilities[1246].

According to Disability Sports NI (DSNI),[1247] people with disabilities remain half as likely to participate in sport and physical activity as non-disabled people in Northern Ireland. Disability Sport NI recommended that momentum is needed to sustain and build on previous achievements by scaling current activity, offering people access to more sports and in more places.

[1242] Sport NI (ND): Active Living: No Limits 2021 (accessed 23 December 2021).
[1243] Disability Action (2017): £500,000 investment in 11 District Council Disability Sports Hubs across NI (accessed 23 December 2021).
[1244] Disability Sport NI (ND): Governing Bodies (accessed 23 December 2021).
[1245] RAISE (2021): Sport and disability in Northern Ireland p.31 (accessed 22 December 2021).
[1246] Sport NI (ND): ISF Accreditation (accessed 23 December 2021).
[1247] DSNI (December 2020): Disability, Sport and Human Rights webinar (accessed 23 December 2021).

Seven athletes from NI participated in the Paralympics. The athletes secured 6 medals including two bronze and two silver[1248]. Sport NI's annual report 2019-2020 refers to four athletes being supported to train, compete, and excel on the world stage[1249].

Sport NI's 2020-2025 corporate plan remains at the consultation stage at the time of writing[1250] .

COVID-19 restrictions have had a particularly negative impact on physical activity levels of d/Deaf and disabled people. Over one third of applicants (33%) to Sport NI's Hardship Grant reported a disability[1251].

The NI Assembly Research and Information Service (RaISe) has identified the following policy considerations:

- 71% of people with disabilities experience exclusion due to access to facilities and equipment;
- the highlighting of 'different kinds of provision' may reinforce negative differences between people with disabilities and non-disabled people;

[1248] Newsletter (2021): NI Paralympians win praise at Tokyo games close: Six medal haul for local athletes (accessed 23 December 2021).

[1249] Disability Sport (NI): Disability Sport NI Annual Report and Draft Accounts 2019/20 (accessed 23 December 2021).

[1250] Sport NI (ND): Corporate plan 2020-2025 (accessed 23 December 2021).

[1251] RAISE (2021): Sport and disability in Northern Ireland, p.4 (accessed 22 December 2021).

- a lack of specialist staff who understand the needs of those experiencing disability and can facilitate involvement in activities.
- the cost of participating in sport, for example, sports that require specialist equipment and additional staff support;
- transport availability to sporting venues and competing time constraints of caregivers and helpers; segregation between governing and funding bodies e.g. Disability Sport NI and Sport NI;
- a lack of media representation. Coverage tends to be restricted to competitive sports at national and international levels. This creates an impression that disability sport is only for those at the elite end of the spectrum[1252].

Research undertaken by TEO in 2015[1253] demonstrated that progress in developing sports for individuals with a disability often encounters barriers that limit or impedes people's participation. These can include insufficient financial resources[1254], time, personal support[1255], awareness of programmes, and type of disability.

[1252] Ibid, p.20.

[1253] TEO (2021): Social Exclusion and Sport in Northern Ireland (accessed 23 December 2021).

[1254] TEO (2015): Social Exclusion and Sport in Northern Ireland, p.89 (accessed 23 December 2021).

[1255] Ibid.

For sports organisations, certain practices and procedures create additional barriers that limit participation. These include inaccessible facilities[1256], inaccessible transport[1257], unsuitable programmes, inadequate planning, insufficient support, and outdated social perceptions held by both staff and wider stakeholders[1258]. Policies have tended to focus on merging disability sport organisations and their participants into non-disabled sporting organisations through mainstreaming[1259].

Research undertaken at Ulster University published in 2019[1260] examined the implementation of Sport NI funded mainstreaming policies by Ulster Rugby, the Irish Football Association, and the Ulster Gaelic Athletic Association. Conclusions included:

- poor interpretation of mainstreaming, possibly due to a lack of any specific targets and an overall strategy to support funding recipients on 'how' to approach implementation;

[1256] Ibid.

[1257] Ibid.

[1258] Ibid.

[1259] Ibid, p.90, pp.125-128.

[1260] Kitchin, P.J., Peile, C. and Lowther, J. (2019): Mobilizing capacity to achieve the mainstreaming of disability sport, Managing Sport and Leisure, 24:6, pp. 424-444 (accessed 23 December 2021).

- awareness of the mainstreaming policy within the sporting organisations was either superficial (Irish Football Association, Ulster Gaelic Athletic Association) or non-existent (Ulster Rugby);
- none of the three organisations had fully consulted with people with disabilities. Strategic targets around consultation could have enhanced performance;
- programmes offered by disability type (e.g. blind football) limited options for individuals with specific impairments, rather than an offering that is available to a broader spectrum of disabilities;
- the performance framework only loosely articulated what success would look like, which relied heavily on output targets, such as the number of training sessions delivered.

The study also noted that differences emerged once the mainstreaming of funding was discontinued. Gaelic, Football and Sports Associations sustained their programmes and incorporated them into their wider sport development offerings, while rugby discontinued provision, including ending the contract of the manager.

The Northern Ireland Sport and Human Rights Forum was created and launched in May 2019. Ulster Gaelic Athletic Association (GAA), Ulster Rugby, and the Irish Football Association (IFA) are among its members. The Forum was set up to facilitate the exchange of knowledge and good practice on sport and human rights issues[1261].

The Department for Communities is developing a new 10-year sports and physical activity strategy which will be cross-departmental and focus on linkages between sport and physical activity and other policies of the Executive, such as physical and mental health and well-being, education, transport, urban and rural regeneration, good relations, community safety, social inclusion; and economic and social equality[1262]. The consultation process concluded in May 2021. The strategy had not been issued ed at the time of writing[1263], publication having been postponed due to COVID-19[1264].

[1261] NIHRC (2021): NI Sport and Human Rights Forum celebrates Good Relations Week 2021 (accessed 23 December 2021).

[1262] DfC (ND): A new Sport and Physical Activity strategy (accessed 23 December 2021).

[1263] DfC (ND): Consultation on a new Strategy for Sport and Physical Activity (accessed 23 December 2021).

[1264] RAISE (2021): Sport and disability in Northern Ireland, p.4 (accessed 22 December 2021).

The equal treatment of d/Deaf culture and language under Article 30 (4) of the Convention has been an issue of longstanding concern within NI[1265]. Recognition of sign language and d/Deaf culture has been addressed under the section above pertaining to Article 21[1266] freedom of expression and opinion and access to information in this report. The participation of children and young people in play is addressed within commentary with respect to progress with regard to Article 7 in this report.

The authors of this report propose the following recommendation:

- investment in specialist staff who understand the needs of d/Deaf and disabled people alongside capital resources to ensure that d/Deaf and disabled people can participate in sport and leisure.

[1265] Harper, C., McClenahan S., Byrne, B. and Russell, H. (2012): 'Disability Programmes and Policies: How Does Northern Ireland Measure Up?', p.248 (accessed 22 December 2021).

[1266] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly (Article 21) (accessed 4 November 2021).

Article 31: Statistics and Data Collection

Article 31 UNCRPD requires all State parties to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the UNCRPD[1267]. The UNCRPD Committee has expressed concerns, in its (2017) concluding observations, about the absence of unified data and indicators with respect to deaf and deaf and disabled people[1268]. There are significant gaps in the collection of disability statistics and limited availability of disaggregated data. There is no official collection of appropriate data related to the lived experience of d/Deaf and disabled people or the impact of changes in legislation with respect to disability in Northern Ireland. This is further compounded by the absence of a clear agreed definition of disability[1269].

[1267] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 31 (accessed 4 November 2021).

[1268] 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, CRPD/C/GBR/CO/, paragraphs 64-65 (accessed 4 November 2021).

[1269] DfC (2020): Disability Expert Advisory Panel Report and Recommendations, p.25 (accessed 15 December 2021).

Indicator 42 of the draft Programme for Government referred to the increase average life satisfaction score of d/Deaf and disabled people as a potential outcome[1270]. The Department for Communities has acknowledged that the comprehensive disaggregated data required to support indicator 42 is lacking[1271]. The Department conducted a scoping study to identify existing data, which noted the limitations of the current data and the requirement to enhance data collection through the creation of new modules added to existing surveys whilst recognising that this should not be the primary means of collecting data with respect to quality of life[1272]. The review had five objectives:

- review the international literature on quality of life (QoL) measurements for people with disabilities and their families;
- develop recommendations for key definitions;
- assess existing and emerging data sources for potential use;
- develop recommendations for a preferred option;
- test the recommended QoL measure[1273].

[1270] NI Executive (2016): Draft Programme for Government Framework p.13 and p.113 (accessed 20 October 2021).

[1271] DfC (2019): Measuring the Quality of Life of Disabled People and their Families Scoping Study Final Report (accessed 5 Nov 2021).

[1272] Ibid, p.62.

[1273] Ibid, p.3.

Among its recommendations is to define QoL as ‘Individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. QoL is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relations to salient features of their environment’[1274].

The scoping study recommended the development of a new measurement tool[1275]. A recommendation was also made to adopting the definition of disability proposed in Article 1 of the UNCRPD, which specifically acknowledges that the presence of multiple barriers may limit the full and equal participation of people with disabilities within society and is supported by many organisations and individuals with disabilities living in Northern Ireland. People have indicated that they like not only the recognition of barriers, but also the broader recognition of types of disabilities and the promotion of full and effective participation on an equal basis with others.[1276]

[1274] Ibid.
[1275] Ibid, p.7.
[1276] Ibid, p.14.

The study concluded that measuring the quality of life of d/Deaf and disabled adults must extend beyond quality-of-life measurement tools[1277]. It is important to note that these proposals do not address the limitations of indicator 42 identified by the Equality Commission[1278]. The Equality Commission queried the appropriateness of indicator 42 for disability while no such proposals have been made in respect of other Section 75 groups[1279]. The Equality Commission proposed the following recommendations:

- the development of an appropriate high-level indicator should be underpinned by indicators which illustrate the extent to which key UNCRPD articles are achieved. Article 31 of the UNCRPD requires State Parties to collect information about people with disabilities, with the active involvement of people with disabilities, so they can better understand the barriers they face;
- the collection of data:
    1. on the prevalence of disability disaggregated by gender;
    2. disaggregated data to measure the impact of all the proposed actions associated with indicator disaggregated by

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[1277] Ibid, p.26.

[1278] ECNI (2017): Equality Commission response to the proposed Delivery Plan for Programme for Government Indicator 42 (Average life satisfaction score of people with disabilities) (accessed 3 January 2022).

[1279] Ibid, paragraph 1, p.1.

respect to the impact of welfare reform and of measures to mitigate associated adverse impacts;

3. put in place a measurement tool to capture the extent to which the rights set out in the UNCRPD articles are realised[1280].

It is important to note that legislative programmes, policies, and practice cannot be effectively developed and monitored in the absence of access to data. The collection of data through which to examine the impact of legislative change on the lives of deaf and deaf and disabled people is absent in Northern Ireland.

The Report of the Disability Strategy Expert Advisory Panel has highlighted several gaps in terms of statistics and data, including limited information in relation to education, employment, and public life. Taking this into account, it difficult to conclude that the Executive is currently meeting this target. That said, the new disability strategy will present an opportunity to address these concerns[1281].

The Disability Strategy Expert Advisory Panel's recommendations include:

[1280] Ibid, paragraph 9c-d, p.6.

[1281] DfC (2020): Disability Expert Advisory Panel Report and Recommendations, p.25 (accessed 15 December 2021).

- 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 and UNCRPD 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;
- d/Deaf and disabled people, including d/Deaf and disabled children, and their representative organisations, should be involved in deciding what data should be collected[1282].

The authors of this report recommend the adoption of the recommendations outlined by the Equality Commission within their response to the proposed Delivery Plan for Programme for Government Indicator 42 (Average Life Satisfaction Score of People with Disabilities) as outlined above[1283].

[1282] Ibid, p.26.

[1283] ECNI (2017): Equality Commission response to the proposed Delivery Plan for Programme for Government Indicator 42 (Average life satisfaction score of people with disabilities) (accessed 3 January 2022).

Article 33: National Implementation and Monitoring

> "*The Articles provide an excellent framework, and this should be built into everything public authorities do to promote, implement, and uphold rights. A public sector kite mark audit based on articles would be a great idea".*
>
> **Disabled man with a long-term health condition aged 50-54.**

Article 33 of the UNCRPD requires State Parties to designate one or more focal points within their system of organisation for matters associated with the implementation of the Convention and to give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels.

State parties are required to establish a framework which should include one or more independent mechanisms to promote, protect and monitor the implementation of the Convention. In the establishment of the mechanism State Parties are required to take account of principles relating to the status and function of national institutions for the protection and promotion of human rights.

Article 33 requires the participation of civic society and DPOs in the monitoring process[1284].

The Committee expressed concern regarding the lack of comprehensive mechanisms and sufficient resources with respect to the implementation of the Convention. The Committee recommends that an appropriate coordinating structure is established which has access to sufficient resources in order to strengthen the implementation of the Convention across the Devolved Administrations.

The Committee raised concerns with respect to the level of resources available for the effective monitoring by the independent monitoring framework noting that this limits the support available to DPOs to participate in monitoring activities. The Committee recommends that the State Party ensures the independence of monitoring mechanisms and provides sufficient funding through which to monitor the implementation of the Convention[1285].

[1284] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, Article 33 (accessed 4 November 2021).

[1285] 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, CRPD/C/GBR/CO/1, paragraphs 68-71 (accessed 4 November).

Since the concluding observations and recommendations were published in 2018, the UN Committee published General Comment No. 7[1286] to clarify how d/Deaf and disabled people should be directly involved in the monitoring and implementation frameworks established by countries who have ratified the Convention. Specifically, this means that d/Deaf and disabled people themselves and their views should be prioritised by independent mechanisms in shaping and informing their work. The Committee's guidance draws on the general obligation in Article 4 of the Convention that d/Deaf and disabled people should be closely involved and engaged in decision-making processes that impact on their lives.

Article 4 (3) [1287] requires State Parties closely consult with and actively involve d/Deaf and disabled people, including children through their representative organisations in the development and implementation of legislation and policies.

[1286] UN Committee on the Rights of Persons with Disabilities (2018): 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 (accessed 18 December 2021).

[1287] UN General Assembly (2007): Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly (Article 4.3) (accessed 4 November 2021).

Paragraph 34 of the UNCRPD Committee's General Comment No. 7, on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention, emphasises that Article 33 of the Convention establishes national implementation mechanisms and independent monitoring frameworks, such as the Independent Mechanism for Northern Ireland and the wider UK Independent Mechanism (UKIM), provide for the participation of d/Deaf and disabled people and DPOs. Article 33 should be read and understood as supplementing article 4 (3).

Paragraph 38 of General Comment No. 7[1288] advises that State Parties should ensure that independent monitoring frameworks allow for, facilitate and ensure the active involvement of d/Deaf and disabled people and DPOs in such frameworks and processes, through formal mechanisms, ensuring that their voices are heard and recognised in its reports and the analysis undertaken.

[1288] UN Committee on the Rights of Persons with Disabilities (2018): 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, paragraph 38 (accessed 18 December 2021).

Paragraph 39 of General Comment No. 7[1289] advises that State Parties should support and fund the strengthening of capacity within civil society. The support and funding of DPOs in relation to article 33 (3) complement States parties' obligations under article 4 (3) of the Convention and do not preclude them.

There is at present no co-ordinated strategy for the incorporation of the UNCRPD into law[1290]. Progress is therefore ad hoc and challenging to monitor. It is hoped that this would be addressed within the proposed Disability Strategy.

There has been no additional funding allocated to IMNI or UKIM to engage d/Deaf and disabled people effectively and properly in the independent monitoring of the Convention[1291].

IMNI has proactively responded to the intention set out in paragraph 38 of General Comment No. 7 by establishing a Disability Forum[1292] to advise and support them in the monitoring and implementation of the Convention.

[1289] Ibid, paragraph 39.

[1290] DfC (2020): Disability Expert Advisory Panel Report and Recommendations, p.13 (accessed 15 December 2021).

[1291] Ibid, p.16.

[1292] ECNI (2021): Disability Forum.

The new IMNI Disability Forum was established in March 2021[1293]. The purpose of the Forum is to assist the IMNI in their work to fulfil the independent monitoring role within Article 33 and to inform and co-ordinate engagement with the State Party towards supporting and challenging government to give effect to the UNCRPD in NI. The establishment of the Forum sought to realise the intent of the UNCRPD Committee's general comment no. 7[1294] and the importance of prioritising the views of disabled people. There remain significant challenges, with regard to the monitoring and implementation of the Convention and the ongoing participation of DPOs within the Forum:

- there are only a small number of DPOs in NI, the majority of whom are represented within the current Disability Forum;
- beyond remuneration for travel expenses and reasonable adjustments, none of the DPOs represented within the Forum are paid for their expertise, because the NI Executive (State party/region) has not funded IMNI to fully meet the requirements of Articles 4 (3) and 33 (3) of the UNCRPD as set out in General Comment No. 7.

[1293] NIHRC (2012): First meeting of IMNI Disability Forum to work on UNCRPD implementation (accessed 3 January 2022).

[1294] UN Committee on the Rights of Persons with Disabilities (November 2017): 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, paragraph 13.

The authors of this report propose the following recommendations with respect to the IMNI Forum:

- in the long term IMNI, may wish to explore consideration of a public appointment style system to involve d/Deaf and disabled people within any future composition of the Forum;

  consider engaging with d/Deaf and disabled people to shadow the existing membership, one year prior to the appointment of membership to the next Forum, to build capacity amongst d/Deaf and disabled people;
- lobby the NI Executive for additional funds to support the DPO's engagement with the Forum including funding directly to DPO's to develop the capacity of these organisations to directly engage with IMNI and the Government.

The Disability Strategy Expert Advisory Panel have proposed the following recommendations:

- DfC should develop a Northern Ireland Disability Forum to work with government, with d/Deaf and disabled people in a leadership role;

- DfC should engage with women, girls, children and young people, older people, ethnic minorities, people with learning disabilities and mental health issues, d/ Deaf and disabled people, and others to consider and respond to the views of d/Deaf and disabled people and their representative organisations;
- DfC should fund and support the operation of DPOs to engage effectively in decision making and support the expansion of DPOs across NI and fund 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 UNCRPD Committee's recommendations set out in paragraph 94;
- "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 recommendations in paragraph 94 of General Comment No. 7 and adopt most, if not all, of them including recommendation (a) with regard to "legal capacity"[1295].

[1295] DfC (2020): Disability Expert Advisory Panel Report and Recommendations pp.18-19 (accessed 15 December 2021).

Conclusions

This research has provided an overview of the current position regarding progress with respect to the obligations and provisions in the UNCRPD in NI. In so doing, it has taken explicit account of both the UNCRPD articles and the subsequent observations made by the UN Committee in 2017. Ultimately, the research has identified a range of shortfalls in delivery in Northern Ireland relative to the UNCRPD and has outlined recommendations for change. This report provides information to IMNI to assist with the independent monitoring role with respect to the UNCRPD.

Previous reports employed a prioritisation framework to identify which rights were considered to be most pressing. The authors of this report did not employ such an approach. Rather, the report benchmarks progress across the majority of articles within the UNCRPD and promotes the voice of d/Deaf and disabled people.

Progress with respect to the Disability Strategy will be core to the realisation of the rights and protections within the UNCRPD. At the time of writing, there are concerns that the cross-departmental aspects of the strategy combined with reductions in the Executive Budget could slow progress.

Covid-19 has brought the importance of the UNCRPD to the fore emphasising the need to protect the lives of d/Deaf and disabled people and to ensure equal recognition before the law. The extent of abuse in Muckamore Abbey provides an urgency to ensuring that the rights of d/Deaf and disabled people are upheld. It is also worth noting that this report is the third in a series of reports on progress with respect to the UNCRPD which has called for similar protections for d/Deaf and disabled people in NI to those which d/Deaf and disabled people in the rest of the UK enjoy.

Welfare reform continues to have significant adverse impacts on the right of d/Deaf and disabled people to an adequate standard of living. The mitigations package and the actions taken to close the gaps within the package are welcome and provide protections but do not address all of the adverse impacts of welfare reform.

Accessibility continues to pose significant challenges to independent living. It is hoped that this report will act both as a source of evidence and a stimulus for change.

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