Mind the Gap

Barriers to the realisation of the rights of children with disabilities in Ireland

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Foreword

Children with disabilities are one of several groups of children that the Ombudsman for Children's Office has been paying particular attention to through the work we are doing under our current Strategic Plan. This is because we know that children with disabilities are among those children who can face multiple barriers to enjoyment of their rights.

Through our work we hear first hand from children with disabilities and their families about the uphill battles they face. Battles to secure suitable housing. Battles to find an appropriate school place or to access suitable school transport. Battles to get necessary aids and appliances. Battles to receive mental health care when it's needed. Battles to obtain a timely assessment of needs and to get the services recommended on foot of an assessment.

From a children's rights perspective, such battles throw two things into sharp relief. On the one hand we see families treating the best interests of their children as their basic concern and doing everything they can to support their children to develop, thrive and reach their potential. On the other, we see the State falling short, time and again, when it comes to fulfilling its obligations to those children with disabilities.

In this regard, it is important to remember that the State has primary responsibility for implementing children's rights, including the rights of children with disabilities. This means that the onus is on the State to undertake all appropriate legislative, administrative, and other measures to implement children's rights. When it comes to social, economic and cultural rights, it means that the State is obliged to undertake such measures to the maximum extents of its available resources. Put simply, when it comes to making children's rights real in children's daily lives, the State's duty is to lead, not impede.

We understand that fulfilling this duty is easier said than done. We know, for example, that the task of securing adequate financial resources is a perennial challenge and we are aware of persistent difficulties in recruiting and retaining key personnel, including mental health professionals, physiotherapists, occupational therapists, and speech and language therapists.

However, the barriers children and their families are battling are not attributable to resource deficits alone. We know from our own work, including our investigations of Molly's case and Jack's case and our work on assessment of need, that these barriers are also bound up with other matters, including poor planning, poor interagency coordination and collaboration, and poor data collection. That is what led us to commission new research to examine what other obstacles does the State place in front of children with disabilities?

This current research, which has been undertaken for us by researchers at the Centre for Disability Law and Policy and the Institute for Lifecourse and Society at NUI Galway, broadens and deepens our understanding of the barriers that children with disabilities in Ireland face when it comes to enjoying their rights.

The overarching conclusions reached by the researchers could hardly be more stark:

- Children with disabilities are overlooked in many child- and disability-focused laws, policies and programmes.
- Children with disabilities are not actively or effectively involved in consultations on many existing laws, policies and programmes affecting them.
- Children with disabilities are relatively invisible in data.

If the State is to fulfil its duty to realise the rights of children with disabilities, it must know, see and hear these children.

Additional, specific measures are recommended by the researchers to address barriers that children with disabilities face to enjoying their rights, including their rights to equality and non-discrimination, family and care, health and welfare, education, play, privacy and access to justice.

I wish to thank the research team for their work. This research is a valuable resource that we will draw on as we pursue our efforts to progress the realisation of the rights of children with disabilities.

The State is currently working to prepare reports to the UN Committee on the Rights of the Child and the UN Committee on the Rights of Persons with the Disabilities on the progress it is making to implement its obligations under the UNCRC and the UNCRPD. Accordingly, I hope that legislators, public policy-makers and service providers will give their full attention to the findings of and recommendations arising from this research.

It is high time for children with disabilities and their families to stop having to battle barriers. It is high time for the State to lead, not impede.

Niall Muldoon

Dr. Niall Muldoon,
Ombudsman for Children

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1. Executive Summary

This report has been commissioned by the Ombudsman for Children's Office and prepared by researchers at the Centre for Disability Law and Policy and Institute for Lifecourse and Society, NUI Galway. The purpose of this report is to explore the key barriers to the realisation of rights for children with disabilities in Ireland and to propose positive measures which can address these barriers appropriately and effectively. Research conducted for this research has been grounded in a human rights framework, guided by the provisions of the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. As a result, as explained in the Introduction, the research uses a broad conceptualisation of children with disabilities, inclusive of children with chronic or long-term health conditions and children with experience of mental health services.

The report is structured as follows. Sections 1–4 set out the report's introduction, research questions, methodology and a profile of children with disabilities in Ireland. Section 5 covers overarching & cross-cutting rights (equality and non-discrimination, participation and accessibility). Sections 6–9 address the respective Clusters of Rights, Development (including Education and Play), Inclusion and Belonging (including Families, Housing and Transport), Health and Welfare (including Life, Health and Adequate Standard of Living) and Justice and Redress (including Liberty and Security, Access to Justice, Privacy, Freedom from Exploitation, Freedom of Expression). Finally, Section 10 sets out the report's conclusions.

Research conducted for this report has been solely desk-based. However, this research has found several instances whereby children with disabilities have not had any documented opportunities to participate in the development of legislation, policy and programmes which affect their lives. This is a major issue which the publication of this report seeks to highlight and one which requires urgent action and commitment from the State to address. Another common finding of the research, which is reflected in this report's conclusion, is that children with disabilities are often overlooked both within disability law, policy and programmes, and children's rights initiatives (including legislation, policy and practice). This report aims to draw attention to the need for more targeted legislative, administrative and other measures directed at children with disabilities to reflect the realities of their lives and ensure that their human rights are respected. This report can therefore act as a starting point for further State action designed to ensure the inclusion of children with disabilities in laws, policies and practices which affect them, and respect, protect and fulfil their human rights under both the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities.

2. Introduction

The purpose of this report is to document the findings of a desk-based literature review to address the following research questions:

1. What are key barriers to the realisation of the rights of children with disabilities in Ireland?
2. What measures are required to address these barriers appropriately and effectively?

An understanding of the State's key international obligations informed our overall approach in this report. Following Ireland's ratification of the UN Convention on the Rights of the Child (UNCRC) in 1992, and of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018 the State is required:

- 'to undertake all appropriate legislative, administrative and other measures' for the implementation of children's rights (UNCRC, article 4), and
- 'to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability' (UNCRPD, article 4) and
- 'in the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations' (UNCRPD, article 4.3).

Article 7 of the UNCRPD is particularly relevant as it builds on UNCRC provisions by providing more explicit detail of how these should be applied to children with disabilities and requires positive action by states to implement these rights:

> 'States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children'.

Embedding positive obligations in legislation is a vital step in ensuring that the State fulfils its duty to realise the rights of children with disabilities. Therefore, our approach considered developments in legislative measures in Ireland to uncover the rights and gaps in rights protection that children with disabilities are entitled to according to international standards. Rights in law also provide a clear framework to support a child-centred approach in the delivery of services impacting on the rights of children with disabilities. In this context we examined policy and practice measures to identify where rights are being ignored, and the barriers that lead to this denial of rights for children with disabilities.

Introduction to the UNCRPD

Ireland ratified the UNCRPD on the 20 March 2018. The first State Party report was due to be submitted to the Committee in April 2020, consequently UNCRPD Concluding Observations will not be available potentially until 2021 at the earliest. The overarching issue facing Ireland regarding disability at the moment, is the need to establish domestic legislative compliance with the UNCRPD. The government is drafting a range of legislation to address issues around equality and non-discrimination that can potentially bridge equality gaps and feed into compliance with the UNCRPD. One example relevant to accessibility is the Health (Transport Support) Bill, which will address the needs of those with a disability, including children, to meet their mobility costs around access to work or school.

While Ireland ratified the UNCRPD, the government did not ratify the Optional Protocol (OP) that allows individuals to make complaints against Ireland to the UN Committee on the Rights for Persons with Disabilities.[1] As a result, Inclusion Ireland, highlighted that the Irish Human Rights and Equality Commission (IHREC), as Ireland's independent monitoring mechanism, must put pressure on the government to ratify the OP.[2]

The UNCRPD protects a range of civil, political, economic, social and cultural rights as they relate to persons with disabilities, including children with disabilities. The main purpose of the Convention is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disabilities, and to promote respect for their inherent dignity'.[3]

The UNCRPD does not include a definition of disability. However, the Preamble and article 1 clarify the scope and application of the Convention. The Preamble recognises that 'disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'.[4] Moreover article 1 provides that:

> 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

The UNCRPD is founded upon the principles outlined in article 3 and of particular relevance for children with disabilities are the principles of non-discrimination,[5] inclusion and participation,[6] respect for inherent dignity, individual autonomy including the freedom to make one's own choices,[7] and respect for their evolving capacities.[8]

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[1] Citizens Information Board, *Disability legislation update* (2018) 45(4) *Relate* 2.

[2] Inclusion Ireland, *Submission to the Irish Human Rights & Equality Commission on IHREC's Strategy Statement 2019–2021* (2018) 8.

[3] UNCRPD, art 1.

[4] UNCRPD, Preamble para (e).

[5] UNCRPD, art 3(b).

[6] UNCRPD, art 3(c).

[7] UNCRPD, art 3(a).

[8] UNCRPD, art 3(h).

The protection of human dignity and equality are central to the interpretation and application of the rights in the UNCRPD.[9]

Introduction to the UNCRC

The UNCRC was adopted by the General Assembly of the United Nations on 20 November 1989.[10] The UNCRC was the first binding instrument to merge the categories of human rights, including civil, political, economic, social and cultural rights as well as aspects of humanitarian law. There are three Optional Protocols to the UNCRC and of particular interest is the third Optional Protocol on Individual Communication (OPIC).[11] OPIC has introduced a new procedure and revitalised the UNCRC and its obligations on States Parties. Children have a new right, one that gives them access to complain to the UNCRC Committee if there is a violation of their rights. This new individual communication procedure will strengthen the implementation of the UNCRC by providing direct access for children to the UNCRC Committee once they have exhausted domestic remedies. States must take notice and listen to the voice of the child.[12]

Ireland has also accepted the individual complaints mechanism under the Optional Protocol to the UNCRC on a communications procedure (OPIC).[13] This is significant for the progression of children's rights as the OPIC encourages State Parties to develop national mechanisms to enable children to have effective remedies for violations of their rights.

The UNCRC defines a child as every human being below the age of 18 years unless, under the law applicable to the child, majority is attained earlier.[14] The introduction of the UNCRC marked a shift in society's attitude, from the historical perceptions of children as passive dependents to viewing children as deserving of individual status and rights. The articles of the UNCRC are generally grouped into four categories of rights and a set of guiding principles. The four categories are participation, provision, protection and prevention.[15] There are also four general principles underpinning the UNCRC, and together they provide guidance for State Parties on how to interpret and implement the Convention.

The general principles are enshrined in articles 2 (non-discrimination), 3 (best interests), 6 (life, survival and development) and 12 (participation). The principle of non-discrimination provides that all children are entitled to equality of opportunity, and this means that children with disabilities should be given the same opportunity as other children to enjoy all rights in the UNCRC.[16] The right to life, survival and development

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[9] Annagret Kampf, 'Involuntary Treatment Decisions: Using Negotiated Silence to Facilitate Change?' in Bernadette McSherry and Penny Weller (eds), *Rethinking Rights-Based Mental Health Laws* (Hart Publishing 2010) 139.

[10] Adopted and opened for signature, ratification and accession by General Assembly Resolution 44/25 of 20 November 1989 entry into force 2 September 1990, in accordance with art 49.

[11] On 19 December 2011, the UN General Assembly approved a third Optional Protocol on a communications procedure, which will allow individual children to submit complaints regarding specific violations of their rights under the Convention and its first two optional protocols. The Protocol entered into force in April 2014.

[12] Ireland signed and ratified the Third Optional Protocol on a Communications Procedure in 2014.

[13] Optional Protocol to the UNCRC on a communications procedure (accepted, September 2014).

[14] UNCRC, art 1.

[15] Thomas Hammarberg, 'The UN Convention on the Rights of the Child-and How to Make it Work' (1990) 12 Human Rights Quarterly 97.

[16] UNCRC, art 2 and 23.

is to be interpreted in the broadest sense to include mental, emotional, cognitive, social, physical and cultural development. Survival and development rights require the government to provide resources and access to the means necessary to fulfil these rights.

Framework supporting implementation of the UNCRC and UNCRPD

The UNCRC Committee's General Comment No. 5 General Measures of Implementation provides a framework from which a rights-based approach to the realisation of children's rights can be viewed. This report has considered the guidance in General Comment No. 5 when reviewing Irish law and policy to identify the barriers to the realisation of the rights of children with disabilities, and the measures that could be taken to overcome these barriers. The UNCRC Committee in this General Comment urges State parties to ratify other relevant international instruments,[17] such as the UNCRPD. It is clear that there must be synergy between international human rights instruments, particularly when considering the principles of indivisibility and interdependence of human rights. In this context the report also looks to the UNCRPD indicators[18] to frame our approach when making suggestions for measures to ensure effective implementation of the rights that children with disabilities are entitled to across both UN Conventions.

Concept of Disability

Across international human rights instruments and national law and policies which relate to the rights of children with disabilities the conceptualisation of disability has been varied. In order to address this and to apply a rights-based analysis to the barriers to the realisation of the rights of children with disabilities, this report applies the human rights-based approach to disability.

Historically, international human rights instruments (UNCRC), laws and policies adopted the medical model of disability which placed a primary focus on the impairment or medical condition and how it could be cured or improved. With the growth of the disability movement came the social model of disability which argued that society disabled people due to its constructs and design.[19] This approach was the basis for the drafting of the UNCRPD and is clearly articulated in the UNCRPD preamble, 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others', and in article 1, 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' The social model has since been embraced by the

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[17] UN Committee on the Rights of the Child, General Comment No. 5 (2003): General measures of implementation of the Convention on the Rights of the Child (CRC/GC/2003/5) para 17.

[18] Office of the High Commissioner for Human Rights, 'Bridging the Gap: Human Rights indicators for the Convention on the Rights of Persons with Disabilities in support of a disability inclusive 2030 Agenda for Sustainable Development' (Geneva, 2019).

[19] Anna Lawson and Mark Priestley, 'The social model of disability: Questions for law and legal scholarship?' in Peter Blanck and Eilionóir Flynn (eds), *Routledge Handbook of Disability Law and Human Rights* (Routledge 2016).

UNCRC Committee in General Comments[20] and concluding observations.[21]

The basis for this report, the human rights model, captures the broad conceptualisation of disability found under article 1 UNCRPD. The human rights model builds on the social model of disability to provide a more comprehensive solution to the issues faced by the disability community.[22] The approach goes beyond anti-discrimination law by embracing a vast array of 'indivisible and interdependent' civil, political and economic, social and cultural rights[23] and is therefore the ideal platform from which to analyse the barriers to the realisation of rights for children with disabilities.

With this in mind; our approach includes a consideration of how the newest international Convention, the UNCRPD, serves to reinforce and complement the human rights to which children with disabilities are entitled under existing international human rights standards (UNCRC).

Clusters of Rights

Due to the number of rights children with disabilities hold under the UNCRC and the UNCRPD and the vast array of barriers and measures that could be identified in the material gathered and its analysis, the report for this project is structured across clusters of rights. The following four clusters and a category of overarching cross-cutting rights are will be used in this report: Cluster 1 – Development; Cluster 2 – Inclusion & Belonging; Cluster 3 – Health & Welfare; and Cluster 4 – Justice/Redress & Safeguards.[24]

Cross-cutting rights: Equality and non-discrimination; Participation; and Accessibility.

In addition to the accountability of duty bearers noted above, the participation of rights holders through an accessible society in which they live, and equality and non-discrimination are identified as the three main principles underpinning the adoption of a rights-based approach to children with disabilities. These three cross-cutting issues are pre-conditions to the exercise of all other rights and therefore justify focused attention initially, separate from the clustered rights. It is our belief that these cross-cutting issues have an impact on the realisation of rights for children with disabilities across the other four clusters.

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[20] UN Committee on the Rights of the Child, General Comment No. 9 (2006): The Rights of Children with Disabilities (CRC/C/GC/9, 2007) 13 - 14.

[21] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3–4) 10 – 11.

[22] Theresia Degener, 'Disability in a Human Rights Context' (2016) 5(3) Laws 35.

[23] ibid.

[24] See annex 1 of this report for a detailed overview of the rights considered under each Cluster.

3. Research Question and Methodology

The research sought to address the following research questions:

1. What are key barriers to the realisation of the rights of children with disabilities in Ireland?
2. What measures are required to address these barriers appropriately and effectively?

In this regard, the purpose of the research was not to analyse and assess the extent to which Ireland is meeting its obligations to children with disabilities under relevant international standards (UNCRC and the UNCRPD). Rather, our intention is that, by identifying the key barriers and the corresponding actions needed to address these barriers, the research provides a clear, authoritative, up-to-date, evidence-based roadmap for action by key stakeholders.

The principal methodology was a desk-based literature review. This incorporated a socio-legal approach to conducting a rights-based analysis of law, policy and practice from the perspective of the rights of children with disabilities. The main body of research for this report was conducted during the summer of 2020, and the final draft was submitted to OCO in October 2020. Ireland published its Initial Draft State Report on the CRPD in December 2020.[25] The research team revisited our work in light of the Draft Initial State Report, and have added some references to additional policy initiatives mentioned in the report throughout this document. However, some laws, policies or practices which were included in the Draft Initial State Report may not be reflected in this research because they did not relate to a specific barrier, measure or promising practice that was particularly relevant for children with disabilities.

Thematic Literature Review

The research team examined relevant international standards and law, policy and practice in Ireland to identify the barriers, measures and examples of promising practices in securing effective realisation of the rights of children with disabilities. In order to conduct a review of academic literature, the research team searched the following legal databases – HeinOnline, WestLaw, Justis, LexisNexis and vLex, using a variety of search terms intended to capture the wide scope of this research project. There was also a review of any significant grey literature published outside of the traditional academic / journal contexts concerning realisation of rights for children with disabilities, including government reports, policy statements, issue papers, Disabled Persons Organisation and Civil Society Organisation reports, and relevant media coverage.

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[25] Department of Children, Equality, Disability, Integration and Youth, *Draft Initial Report under the Convention on the Rights of Persons with Disabilities: Ireland* (Dublin: December 2020).

In order to capture scholarly literature on barriers and/or measures for the realisation of the rights of children with disabilities which has not been published in legal journals, academic databases such as Scopus (Web of Science), SocINDEX, ASSIA and Google Scholar were also included. Subject specific journals of relevance to this research topic, such as the International Journal of Children's Rights, Childhood and Society, and Disability and Society were also used.

Given the parameters of this research project, the research team needed to go beyond the generic legal and scholarly databases to find up to date information on the measures necessary to realise the rights of children with disabilities in Ireland. Therefore, the following sources of information were reviewed in order to find examples of laws, policies and practices in need of reform in order to meet the requirements of the UNCRPD, and the UNCRC, and those which may provide guidance for measures to overcome identified barriers.

- Concluding Observations of the UNCRPD Committee (the review focused primarily on article 7 but used search terms to review observations on other UNCRPD articles which address issues identified in the clusters for children with disabilities),
- Concluding Observations of the UNCRC Committee (the review focused primarily on article 23 but used search terms to review observations on other UNCRC articles which address issues Identified in the clusters for children with disabilities),
- State Party submissions to the UNCRPD and UNCRC Committees (including those from states, civil society and National Human Rights Institutions), and
- Shadow Reports to the UNCRC and UNCRPD Committees from civil society organisations and independent monitoring mechanisms were also included in the research with a focus on material relevant to the research topic.

Previous research in this area has identified an absence of recent, reliable data in the area of children's rights[26] and disability rights as a barrier in itself. This was also the case in the compilation of the present report and the researchers drew on their extensive networks in these fields to access pre-publication reports or other relevant materials from key stakeholders, professionals and representative bodies in an effort to address these gaps.

The search terms used were selected to ensure that the results are relevant to the study. For example, search terms included subject (children with disabilities) terms (e.g. rights, barriers, measures, strategies, education, health, mental health, housing, juvenile justice, access to justice, equality, participation, best interests, children in care) and population-specific terms to capture specific impairment sub-groups including (blind children, visually impaired children, children with intellectual disability, psychosocial disability, neurodiversity, deaf, hearing impaired, physical and sensory impairment) about whom the research has been conducted.

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[26] Ursula Kilkelly, 'Barriers to the Realisation of Children's Rights in Ireland' (Dublin: Ombudsman for Children's Office, 2007) 14.

4. Profile of Children with Disabilities in Ireland

Data on children with disabilities

According to Census 2016, the number of people with a disability increased by 47,796 between 2011 and 2016.[27] The total number of people with a disability in Ireland stood at 643,131 in April 2016, accounting for 13.5% of the population. 51.6% (331,55) were females and 48.4% (311,580) were males with a disability.[28] The number of children under the age of 18 stood at 75,963. Since 2011 there was an increase of 15.6% (11,828 persons) among those under 20 with a disability.[29] This represented a disability rate of 6.7% in this group. Disability was more common amongst males in all age categories up to age 24, peaking in the 5–9 age groups where there were almost twice as many disabled boys (14,964) as girls (7,887).[30]

10,032 children and young people between the ages of 0–19 were registered on the National Intellectual Disability Database (NIDD) in 2017. 2.7% of the individuals with disabilities registered with the database were in the 0–4 age group, 10.1 % in the 5–9 age group, 11 % in the 10–14 age group and 11.5 % in the 15–19 age group.[31] The services most availed of by children with disabilities were speech and language therapy, occupational therapy and physiotherapy.[32] Lower numbers for children under the age of 18 were registered on the National Physical and Sensory Disability Database (NPSDD) 2017. Out of 9,956 cases on record, 2,986 were under the age of 18, with girls accounting for 1,140 and boys for 1,846 cases.[33] Primary diagnostic categories for service users under the age of 18 included Nervous System (961 cases), Communication (859 cases) and Intellectual/developmental (310 cases), followed by Congenital (204 cases), Musculoskeletal system (175 cases) and Ear complaints (159 cases).[34] However, both NIDD and NPSDD are limited databases, as they only record individuals in receipt of certain kinds of disability services, including residential services and day services. The HRB published its first report from the merged databases in September 2020 indicating that in 2019, there were 6,452 children with disabilities in receipt of disability services (this includes children with intellectual disabilities, autism, developmental delay, mental

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[27] Central Statistics Office, 'Census of Population 2016 Results Profile 9 - Health, Disability and Carers' <https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9d/> accessed 15 May 2020.

[28] ibid.

[29] ibid.

[30] Central Statistics Office, 'Press Statement Census 2016 Results Profile 9 - Health, Disability and Carers' (2 November 2017) <https://www.cso.ie/en/csolatestnews/pressreleases/2017pressreleases/pressstatementcensus2016resultsprofile9-healthdisabilityandcarers/> accessed 15 May 2020.

[31] Health Research Board, 'National Intellectual Disability Database-Annual Report 2017' (Dublin, 2017) 11.

[32] Health Research Board, 'National Intellectual Disability Database-Annual Report 2017' (Dublin, 2017) 13.

[33] Health Research Board, 'Annual report of the National Physical and Sensory Disability Database 2017' (Dublin, 2018) 12.

[34] ibid 13.

health issues, physical and sensory disabilities).[35] Of these, 1,006 were aged 0–4, 3,274 were aged 5–12 and 2,172 were aged 13–17.[36] No further breakdown of the 2019 HRB figures on children with disabilities is yet available by disability type.

The Mental Health Commission publishes information on the number of children admitted to approved centres under the Mental Health Act. According to its 2019 report, the number of children receiving in-patient psychiatric treatment that year was 497 (increased from 408 in 2018).[37] This report also notes that in 2019 there were 54 children detained on adult wards, although 23 of these admissions were for less than 48 hours.[38] Jigsaw notes in its Annual Report 2018 (the most recent year for which an annual report has been published) that it provided mental health support services to 6,356 children and young people aged 12–25.[39] No further breakdown of this figure is available including the proportion of people under 18 who benefitted from Jigsaw's support services.

Budget

According to the Department of Public Expenditure and Reform, 13.4% (€7,195 million) of Government expenditure was invested in disability and special education supports across Social Protection, Health, and Education in 2017.[40] It is not known how much of this disability budget was spent on children specifically. From 2011 to 2017, the total expenditure in this area increased by 16.7% (€1,032 million) and provided a range of supports to a large number of recipients, although no further disaggregated data is available to show the proportion of funding allocated to children with disabilities.[41] In 2017 the HSE allocated €1,689 million for the provision of disability services. The majority of this expenditure, around two-thirds, related to residential services, with another 20% of funding allocated for the provision of day services.[42]

Special educational needs expenditure increased to €1.68 billion between 2011 and 2017, an increase of 38% (€464 million).[43] The majority of special education expenditure related to pay. The Department of Public Expenditure and Reform notes that 'a significant proportion of this is attributable to the nature of resource teacher provision and special needs assistants, and the increases in special classes established'.[44] During the period 2011–16, the number of pupils with an Autism Spectrum Disorder (ASD) diagnosis increased by 83%.[45] Since 2004, special educational needs expenditure has increased by almost 260%.[46] A further budgetary review in 2019 which focused solely on special educational needs funding found that special educational needs expenditure

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[35] Claire Casey, Michael O'Sullivan, Sarah Fanagan, Anne Doyle, 'National Ability Supports System Bulletin 2019' (Dublin: Health Research Board, 2020).

[36] ibid 4.

[37] Mental Health Commission, *Annual Report 2019, Including Report of the Inspector of Mental Health Services* (Dublin 2019) 27.

[38] ibid 5.

[39] Jigsaw, 'Annual Report: Delivering Services' (Dublin, 2018).

[40] Department of Public Expenditure and Reform, *Spending Review 2017 Disability and Special Education Related Expenditure* (Dublin, 2017).

[41] ibid.

[42] ibid.

[43] ibid.

[44] ibid.

[45] Department of Public Expenditure and Reform, *Spending Review 2017 Disability and Special Education Related Expenditure* (Dublin, 2017).

[46] ibid.

represents over 19% of the Department of Education and Skills budget at €1.8 billion expenditure for 2018.[47]

The HSE National Service Plan (NSP) 2018 disability services budget of €1.772.1 billion was increased by €80.4 million to give a closing recurring budget of €1.852.5 billion in 2018.[48] The 2019 budget also provided €15 million for a once-off resourcing of disability emergency places for both adults and children from the Department of Health's own funds. [49] A total of €1.904 billion was to be allocated by the HSE for disability services in 2019.[50] However, no information is available on what proportion of the HSE's spending on disability services relates to children.

The disability budget does not include mental health. In 2018, the then Minister for Health, Simon Harris, and Minister for Mental Health, Jim Daly, committed to allocating €55 million for new developments in mental health in Budget 2019. Between 2012 and 2018 €210 million was allocated for the development of new mental health services.[51] A substantial proportion of this supported the development of community teams in line with A Vision for Change; however, these resources did not meet the increasing demand.[52] In 2017, the HSE had reported the requirement of an additional €98 million to recruit staff for mental health services set out in A Vision for Change. This figure excluded primary care and the voluntary sector investment.[53] No figures are available which relate specifically to the investments made for children within mental health services.

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[47] Department of Public Expenditure and Reform, *Spending Review 2019 Monitoring Inputs, Outputs and Outcomes in Special Educational Needs Provision* (Dublin, 2019).

[48] Dáil Debate, 8 May 2019, vol 982, col 933.

[49] ibid.

[50] Dáil Debate, 9 July 2019, vol 985, no 2.

[51] Houses of the Oireachtas, Joint Committee on Future of Mental Health Care Debate, 4 July 2018.

[52] Mental Health Reform, 'Mental Health Reform Pre-Budget Submission 2019' (July 2018) 2–3.

[53] Mental Health Reform, 'Mental Health Reform Pre-Budget Submission 2019' (July 2018) 2–3.

5. Overarching & Cross-cutting Rights

5.1. Equality and non-discrimination

The principles of non-discrimination and equality are among the most fundamental elements of international human rights law. Equality and non-discrimination are interconnected and are significant rights and principles that must be respected for all children with disabilities on an equal basis with other children. The right to equality and non-discrimination is found in Article 2 of the UNCRC which provides that 'State Parties shall respect and ensure the rights set forth in the Convention without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status'.

Article 2 (2) provides that 'States Parties shall take all appropriate measures to ensure that the child is protected against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions, or beliefs of the child's parents, legal guardians, or family members.' Article 2 prohibits discrimination, including indirect discrimination and discrimination by association. While not clearly addressing multiple or intersecting forms of discrimination, the UNCRC Committee recommend that multiple forms of discrimination should be considered by State Parties.[54] Article 2 (2) allows for positive action to be taken to protect children from discrimination on the basis of the status of caregivers or family members in their lives.

International human rights law, such as the UNCRC, provides States with a framework for taking a rights-based approach in law, policy and practice. A disability rights-based approach aims to prohibit discrimination and promote equality through measures addressing disadvantages within society. The newest international human rights convention of the 21st Century, the UNCRPD, prohibits discrimination and promotes the protection of equality for all persons with disability. Article 5 of the UNCRPD strengthens the UNCRC, by providing more than protection from discrimination for children with disabilities, but also by including multiple and intersecting forms of discrimination, and providing that States should take specific measures in addition to reasonable accommodation to eliminate discrimination and promote equality.

The rights and principles outlined in the UNCRPD are cross-cutting obligations requiring State parties to promote equality and prohibit any form of 'discrimination on the basis of disability'. This means 'any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms'.[55]

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[54] UN Committee on the Rights of the Child, General Comment No. 15 (2013): Article 24: The right of the child to the enjoyment of the highest attainable standard of health, (CRC/C/GC/15) 8.

[55] UNCRPD, art 2.

This includes denying reasonable accommodation where it is needed. These cross-cutting obligations are of immediate realisation.

The general principles of the UNCRPD specifically include non-discrimination and equality of opportunity.[56] In attempts to ensure that the principle of equality is effective, States have introduced non-discrimination legislation, however this alone will not provide for equality of opportunity. According to expert academic commentary: '[t]he current international trend is towards full 'equality of opportunity' for persons with disabilities, entailing structural change, preparing people for greater participation, tackling discrimination in a number of areas and changing social attitudes'.[57] Equality provisions can take different forms. Therefore, it is imperative that States ensure legislation relating to children prohibits discrimination on all grounds and ensures the fulfilment of the rights of children with disabilities on an equal basis with others. This will require States to recognise multiple and intersecting forms of discrimination, including denial of reasonable accommodation as disability-based discrimination.

Reasonable accommodation is defined in article 2 of the UNCRPD as 'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'. Significantly, because the reasonable accommodation duty is embedded in the non-discrimination provision it is a civil and political right and must be incorporated with immediate effect.[58]

It is important to note that the framing of reasonable accommodation in the UNCRPD means that duty-bearers are not required to reasonably accommodate persons with disabilities if to do so would constitute an 'undue burden'. This terminology has been criticised by Kayess and French[59] as having potential negative connotations, such as people with disabilities being labeled as 'burdens'. Despite the concerns of Kayess and French, Lawson believes that the UNCRPD places a heavy emphasis on concepts of reasonableness and proportionality, and therefore the focus should be placed on what modification is reasonable rather than on the cost.[60] While the provision of reasonable accommodation under the UNCRPD has its limitations, it is a much wider concept than what is provided for under Ireland's Equal Status legislation, as discussed below, which states that duty-bearers are not required to reasonably accommodate people with disabilities if to do so would exceed a 'nominal cost'. [61] Therefore, Irish law on reasonable accommodation requires further amendment to meet the standard of the UNCRPD.

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56 UNCRPD, art 3(b) and (e).

57 Gerard Quinn, Theresia Degener, Anna Bruce, Christine Burke, Joshua Costellino, Padraic Kenna, Ursula Kilkenny and Shivaun Quinlivan, *Human Rights and Disability: The Current Use of the Potential of United Nations Human Rights Instruments in the Context of Disability* (Office of the United Nations High Commissioner for Human Rights, 2002) 18.

58 Anna Lawson, 'Disability Equality, Reasonable Accommodation and the Avoidance of Ill-Treatment in Places of Detention: The Role of Supranational Monitoring and Inspection Bodies' (2012) 16(6) International Journal of Human Rights 850.

59 Rosemary Kayess and Phillip French, 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8(1) Human Rights Law Review 1–34.

60 Anna Lawson, 'People with Psychosocial Impairments or Conditions, Reasonable Accommodation and the Convention on the Rights of Persons with Disabilities' (2008) Law in Context 64.

61 *In re Article 26 of the Constitution and the Equal Status Bill* [1997] 2 I.R (SC) 393–396.

5.1.1 Current Irish Context: Overview of law and policy

Regulation in relation to equality and non-discrimination in Irish law is complex. The range of legal instruments governing this issue includes Bunreacht na hÉireann, European Community law, including treaty provisions, the EU Charter of Fundamental Rights, and EU Anti-discrimination Directives. The array further includes the domestic equality legislation in the form of the Employment Equality Acts 1998 to 2015 and the Equal Status Acts 2000 to 2018. There are also non-discrimination provisions in other domestic legislation such as the Education Acts and the Disability Act 2005. Barry notes that 'while children are largely absent from these overlapping and intersecting legal instruments, they nonetheless benefit to varying extents from the provisions that are of general application'.[62]

In Ireland, the right to equality is set out in article 40.1 of the Constitution: 'all citizens shall, as human persons, be held equal before the law.' The Constitution also protects other core fundamental rights important for children with disabilities, including the right to liberty (article 40.4); the right to life (article 40.3.2); family rights (articles 41 and 42); and the rights of the child (article 42A). These rights are interconnected with the right to equality and will be discussed where relevant throughout this report. However, it is important to briefly note the significance of article 42A at this point.

The purpose of the Thirty-first Amendment of the Constitution is to expressly recognise children in their own right within the Constitution. Article 42A affirms each child's inherent rights. The new article aims to remove discrimination between children based on the marital status of their parents. In addition, article 42A is a significant development in Irish law in respect of meeting our international obligations to respect, protect and fulfill children's rights. The incorporation of the right to be heard, and that the best interests of the child shall be the paramount consideration, is a huge triumph for both children in Ireland and their advocates who lobbied vigorously for the inclusion of these rights.[63]

However, although these rights are now enshrined in the Constitution, the narrow wording of the amendment causes concern for the rights of children who do not come within care and family law proceedings. The OCO expressed its reservation with this aspect of the amendment stating that it fails to meet the standard of articles 3 and 12 of the UNCRC.[64]

While article 40.1 may grant a level of protection to the right to equal treatment before the law, the UNCRPD protects the enjoyment of legal capacity on an equal basis with others as part of 'equal recognition before the law' which provides for active participation in legal relationships.[65] Children are often prohibited by law from engaging in legal relationships until they reach the age of majority. Therefore 'equal recognition before the law' can be challenging when applied to children, especially children with disabilities who are often seen as lacking the ability to make legally binding decisions.

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[62] Eilis Barry, 'Non-discrimination and equality' in 'Making Rights Real for Children: A Children's Rights Audit of Irish Law' (Dublin: Children's Rights Alliance, 2015) 7.

[63] Dáil Debate, 18 May 2010, vol 709, no 2.

[64] Ombudsman for Children's Office, *Report to the Oireachtas on the Thirty-First Amendment of the Constitution (Children) Bill 2012* (2012) 13.

[65] Committee on the Rights of Persons with Disabilities, General Comment No. 6 (2018): Equality and Non-discrimination (CRPD/C/GC/6) para 14.

Nonetheless, children with disabilities should be informed, consulted and have their voice heard on an equal basis with non-disabled children, in every decision-making process related to their situation.

It is also important to note that the interpretation and application of article 40.1 by the Irish Courts does not afford much potential for the enforcement of equality rights in the area of economic, social and cultural rights that have particular relevance to children with disabilities. The UNCRPD, like the UNCRC, is a hybrid convention merging both first and second generation rights to ensure rights under the conventions are respected, protected and fulfilled. Ireland will have to reconsider its approach to fulfilling these types of rights to ensure equality between all children.

Equal Status Acts 2000–2018

The Equal Status Acts contain provisions prohibiting discrimination on any of the nine grounds, including disability, in the provision of goods and services, accommodation and education. There are certain exemptions in the legislation. While the term 'child' or 'children' is noted merely five times throughout the Acts, children, with certain exceptions, may seek to rely on any of the discriminatory grounds under the Equal Status Acts. There is a significant exemption in relation to the age ground, which greatly limits the scope of the protection of the Equal Status Acts in relation to children. Section 3(3) provides that treating a child under the age of 18 years less favourably or more favourably than another, whatever that person's age, shall not be regarded as discrimination under the age ground. This section allows less favourable treatment or more favourable treatment for those under 18 years, when compared to over 18, on the age ground but it also allows discrimination as between children of different ages on the age ground. This exemption allows age to be used as 'an arbitrary cut off for the provision of services, irrespective of need and no matter how vital these services may be'.[66]

The definition of disability in the Equal Status Acts is very broad and wider than the equivalent definition in the Disability Act 2005. Therefore, the obligation to provide reasonable accommodation imposed in the Equal Status Act applies to a broad range of children with disabilities.

The Equal Status Acts require the providers of goods and services to do all that is reasonable to accommodate people with disabilities and recognises that refusal or failure to reasonably accommodate constitutes a form of discrimination.[67] They also provide for broad positive action measures to promote equality of opportunity. The provision to provide reasonable accommodation extends to a wide variety of service providers including public service providers, local authorities, schools and other educational authorities. However the extent of the obligation is limited to service provision. The obligation to provide special treatment or facilities only arises in the first place where it would be impossible or unduly difficult for the person to avail himself or herself of the service, without such special treatment or facilities. Therefore, no obligation arises where the person with the disability finds it only moderately difficult to obtain the service.

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[66] Eilis Barry, 'Non-discrimination and equality' in 'Making Rights Real for Children: A Children's Rights Audit of Irish Law' (Dublin: Children's Rights Alliance, 2015) 14.

[67] Equal Status Act 2000, s4.

There is no obligation to provide the special treatment, even if the person with the disability finds it exceedingly difficult to avail of the service, if the provision of the facility or treatment would give rise to more than a nominal cost.[68] This exemption applies even to the State's provision of essential services. Nonetheless it is clear from the case law under the Equal Status Acts that parents seek to use the Equal Status Acts as a means of securing services for children with disabilities.[69] Furthermore, the case law demonstrates that Equality Officers, in interpreting the legislation, have found that what constitutes a 'nominal cost' can vary significantly, depending on the resources of the organisation in question.[70]

Irish Human Rights and Equality Commission Act

An important amendment to the equality legislation, which has potential for children with disabilities, is contained in section 42 of the Irish Human Rights and Equality Commission Act. This requires a broad range of public bodies in the performance of their functions to have regard to the need to eliminate discrimination, promote equality of opportunity and protect human rights. The implications of this duty require on-going impact assessment and guidance from the Irish Human Rights and Equality Commission (IHREC) in the form of guidelines or a code of practice. IHREC also has a number of statutory functions including providing legal advice and representation, and making inquiries, which could be of relevance to children with disabilities whose rights have been violated. IHREC has the potential to assist in the realisation of the equality rights set out in the UNCRC and the UNCRPD.

National Disability Inclusion Strategy 2017–2021

The National Disability Inclusion Strategy (NDIS) 2017–2021 is intended to represent a whole of Government approach to disability and is underpinned by the Disability Act 2005. Accordingly, a wide range of government departments have responsibilities under the NDIS. The policy sets out themes of priority areas with key actions and objectives under each theme and a timeframe for delivery. A key theme in this strategy is equality and choice.[71] However, there is no explicit recognition that any actions will be taken to achieve these objectives for children with disabilities. The theme covers the right of persons with disabilities to equal treatment before the law and to make their own choices and decisions. The rights referred to in this section mainly include those set out in the Assisted-Decision Making (Capacity) Act 2015, which does not apply to children.[72]

The voice of people with disabilities continues to be heard throughout the monitoring and implementation process of the Strategy, in particular through the Disability Stakeholder Group which participates in the monitoring process.[73] However, there is no evidence that the voices of children with disabilities are being recorded in the

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[68] *In re Article 26 and the Employment Equality Bill* [1997] 2 I.R (SC) 360–363.

[69] Eilis Barry, 'Non-discrimination and equality' in 'Making Rights Real for Children: A Children's Rights Audit of Irish Law' (Dublin: Children's Rights Alliance 2015) 16–17.

[70] *A Health and Fitness Club v A Worker* [EED037].

[71] Department of Justice and Equality, *National Disability Inclusion Strategy (NDIS) 2017–2021* (Stationery Office 2017) 11.

[72] ibid 13.

[73] Department of Justice and Equality, *Press Release: Minister McGrath appoints new Disability Stakeholder Group* (17 August 2018) <http://www.justice.ie/en/JELR/Pages/PR18000269> accessed 19 October 2020.

monitoring of this Strategy. This is a gap in policy and practice and requires the State to take measures to ensure the voices of children are heard on an equal basis with other children. For example, mainstream national strategies relevant to children include consultative processes to capture their voices.[74] It is not clear if such processes capture the voices of children with disabilities. Measures to capture voices are required across mainstream and disability specific policies to ensure the realisation of the right to equality in decision-making for children with disabilities.

Better Outcomes, Brighter Futures

Better Outcomes, Brighter Futures is the policy framework for children and young people in Ireland. This policy lists 'equality' as one of its guiding principles and commits to address this for all children, including children with disabilities.[75] However, no specific actions are identified with respect to improving equality and non-discrimination for children with disabilities in the policy – rather, the actions which relate specifically to children with disabilities are more focused on care, disability supports and services, and special education, and do not explicitly address equality and non-discrimination.

5.1.2 Key barriers to the realisation of rights

Legal framework is deficient in providing for children with disabilities right to equality and non-discrimination

Children with disabilities are largely absent from the array of overlapping and intersecting legal instruments that provide for rights protection in the area of equality and non-discrimination. The definition of disability varies across Irish legislation which is confusing and out of step with international human rights concepts of disability. For example, the Disability Act 2005 definition is adult-centred and is not in line with the broad concept of disability under the UNCRPD. The definition of disability under the Equal Status Acts, while broader than the 2005 Act, is based on medical deficit and results in diagnosis led systems which is not compliant with the human rights based understanding of disability under the UNCRPD.[76]

Further limitations of equality legislation for children with disabilities include the failure to recognise age limits which determine eligibility for services as age-based discrimination under the Equal Status Act.[77] This approach has been criticised by the Children's Rights Alliance for failure to recognise children's level of need and how vital certain services may be, including for children with disabilities.[78]

The legal effect of these domestic legal instruments is insufficient to ensure protection under the law for children with disabilities on an equal basis with other children. One example in this regard is the obligation for reasonable accommodation, which is not explicitly recognised as a prohibited form of discrimination in all areas of law.

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[74] Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014–2020* (Stationery Office 2014) 31.

[75] ibid.

[76] Lorraine Leeson and Patrick A. Matthews, 'Submission to the advisory committee on education of the Deaf' (Dublin: Centre for Deaf Studies, 2002).

[77] Equal Status Act 2000, s3(3).

[78] Eilis Barry, 'Non-discrimination and equality' in 'Making Rights Real for Children: A Children's Rights Audit of Irish Law' (Dublin: Children's Rights Alliance, 2015) 14.

General implementation obligations arise from article 2 of the UNCRC. State Parties have an obligation to 'ensure the rights set forth in the Convention without discrimination of any kind...'[79] and to 'take all appropriate measures to ensure that the child is protected against all forms of discrimination...'.[80] This article requires States to identify individual and groups of children, such as children with disabilities that may need special measures to eliminate the cause of discrimination.[81]

Coordination of implementation of the rights of children with disabilities

Silo-ing is a key barrier to the realisation of the right to equality and non-discrimination of children with disabilities. Children's rights and disability rights are being dealt with by separate agencies, through separate policies. In the context of disability, delivery of services and design of policy is primarily through the Department of Health rather than the Department of Justice, whereas general services and supports for non-disabled children has until recently been the responsibility of the Department of Children and Youth Affairs. These parallel approaches have presented a barrier to joined up thinking and realisation of rights of children with disabilities. While there is the potential for improvement in this respect with the emergence of the new Department of Children, Disability, Equality and Integration, it is as yet too early to say what progress may be made. Overall, a lack of focus remains an issue on the needs and rights of children with disabilities in non-disability specific policies and programmes, including outlining positive action measures and the allocation of resources to achieve equality of opportunity for children with disability. This is a recurring barrier under most clusters in this report.

Monitoring, data collection and analysis

Mechanisms to facilitate children with disabilities to participate in the monitoring of laws and policies on equality and non-discrimination are scarce. There are no specific measures in place to capture the voices of children with disabilities in monitoring either the National Disability Inclusion Strategy or Better Outcomes Brighter Futures. There is also limited data available on children with disabilities' experiences of discrimination in Ireland. The research in area of intersectionality and non-discrimination for children in Ireland typically focuses on discrimination with regard to Traveller and Roma, migrant or LGBTI+ children.[82] Children with disabilities are often only included within research on discrimination in education or healthcare contexts, rather than in access to goods and services more broadly.[83]

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[79] UNCRC, art 2.

[80] UNCRC, art 2(2).

[81] UN Committee on the Rights of the Child, General Comment No. 5 (2003): General measures of implementation of the Convention on the Rights of the Child, (CRC/GC/2003/5) 4.

[82] Children's Rights Alliance, 'Report Card 2020: Is the Government keeping its Promises to Children' (2020) 127.

[83] Mary Donnelly and Ursula Kilkelly, 'Child-friendly healthcare: delivering on the right to be heard' (2011) 19(1) Medical Law Review 27.

5.1.3 Measures to overcome identified barriers

Legislation

To ensure the enjoyment of rights on an equal basis with others, the Irish government must take legal measures, including specific measures, to promote the rights and principles guaranteed in the UNCRPD. Legal frameworks outlined above are deficient in responding to the rights of children with disabilities as set out in UN Conventions. An assessment of the current framework to evaluate the extent to which it complies with both UNCRC and UNCRPD is required. This should be followed by amendments to equality legislation to ensure compliance with the latter human rights instruments.[84] Legislation in various areas that impact on the lives of children with disabilities (e.g. family law, health, education, justice, and housing) should explicitly prohibit discrimination on the basis of disability and provide complaints and redress mechanisms to remedy violations.

The introduction of a legislative requirement to collect and publish data disaggregated by disability, including complaints regarding discrimination across all sectors could support monitoring of progress in the field of equality and non-discrimination.[85] This could be introduced as part of new legislation intended to bring Ireland into compliance with the provisions of the UNCRPD (which includes a specific article on data collection), or as an amendment to existing legislation where data collection on disability is already required (e.g. with respect to numbers of persons with disabilities employed in the public sector as mandated by the Disability Act 2005).

Administrative and other measures

The NDIS is more adult-centred than child-centred. As a whole of Government approach to ‘improving the lives of people with disabilities both in a practical sense, and also in creating the best possible opportunities for people with disabilities to fulfil their potential’,[86] it fails to adequately consider the lives of children with disabilities. The Department of Children, Disability, Equality and Integration should consider reviewing the NDIS to be more inclusive of children with disabilities and revising Better Outcomes Brighter Futures to be more inclusive of children with disabilities as well.[87] Measures to capture voices are required across mainstream and disability specific policies to ensure the realisation of the right to equality in decision-making for children with disabilities. All policies and programmes aimed at implementing the right to equality and non-discrimination must have a mechanism for consultation processes to ensure the active involvement of children with disabilities in the design, implementation and monitoring of those policies and programmes.[88] Specific resource-based measures should also include social protection measures to address social exclusion, reduce poverty and/or cover disability related costs so that children with disabilities have full and equal enjoyment of all human rights and fundamental freedoms.

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[84] Office of the High Commissioner for Human Rights, ‘Bridging the Gap: Human Rights indicators - Article 5’ (Geneva, 2019) 5.1.

[85] Office of the High Commissioner for Human Rights, ‘Bridging the Gap: Human Rights indicators - Article 5’ (Geneva, 2019) 5.3.

[86] Department of Justice and Equality, NDIS 2017–2021, p. 1.

[87] EU-OHCHR, article 5 indicator, 5.2.

[88] UNCRPD, GC No. 6 (2018) on equality and non-discrimination (CRPD/C/GC/6); EU-OHCHR, article 5 indicator; CRC GC No5, para 47.

5.2 Participation

Children and young people's participation in decision-making is defined in Ireland as 'the process by which children and young people have active involvement and real influence in decision-making on matters affecting their lives, both directly and indirectly'.[89] This definition is compliant with article 12(1) of the UNCRC and article 7(3) of the UNCRPD. In 2018, the UNCRPD General comment No. 7 on the participation of persons with disabilities, including children with disabilities, stated that, '[t]he Convention on the Rights of Persons with Disabilities recognizes participation as both a general obligation and a cross-cutting issue'.[90]

A distinction has been made between children's participation in personal decisions, affecting the individual child (for example, decisions on their education and medical treatment) and public decisions, affecting children collectively (for example, decisions informing public policy, service review and monitoring). State parties are obligated under the human rights conventions to actively support children with disabilities to participate in personal and public decision-making as well as facilitating their participation in the monitoring of the UNCRPD (art. 33 (3)).[91]

5.2.1 Current Irish Context: Overview of law and policy

Article 42A of the Irish Constitution recognises a child's right to have their views heard in specified circumstances. The article prescribes that legislation should be enacted to ensure that children determined as 'capable of forming of view' will have their views given due weight based on their age and maturity in proceedings to protect the safety and welfare of any child, 'or concerning the adoption, guardianship or custody of, or access to, any child'. Recognition of a child's right to have their views heard is also included in legislation providing for disability service provision and assessments of need[92] and child protection and welfare services.[93] The Education for Persons with Special Needs Act 2004 (EPSEN) includes provisions for a child's participation in educational and transition planning.[94] However, the Act affords a high level of discretion to teachers and special educational co-ordinators regarding a child's participation, particularly with regard to children with higher support needs. Much of the Act, including these provisions, is yet to be commenced and therefore has no legal force. There is also no clear legal framework in Ireland governing a child's consent to or refusal of medical treatment.

The Government's commitment to children's participation in Ireland is underpinned by a National Strategy on Children and Young People's Participation in Decision-making

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[89] Department of Children and Youth Affairs, *National Strategy on Children and Young People's Participation in Decision-making, 2015 – 2020* (Dublin, 2015) 20.

[90] UN Committee on the Rights of Persons with Disabilities, General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7) 1.

[91] See also, ibid and UN Committee on the Rights of the Child, General Comment No. 9 (2006) on The Rights of Children with Disabilities (CRC/C/GC/9) and UN Committee on the Rights of the Child, General Comment No. 12 (2009) on The Rights of the Child to be Heard (CRC/C/GC/12).

[92] Disability Act 2005, s8(8)(c)(i).

[93] Child Care Act 1991, s3(ii) and 24(b); Child and Family Agency Act 2013, s9.

[94] Education for Persons with Special Educational Needs Act 2004, s8(4)(a) and s15(2)(a).

2015–2020 and an accompanying Action Plan, developed by the DCYA[95]. The goal of the strategy is to ensure that children and young people have their views heard at both the individual and collective level, across the national outcome areas set out in Better Outcomes, Brighter Future, National Policy Framework for Children and Young People. The Strategy recognises that, to embed a child's right to have their views heard, requires a cross-Government response. Thereby, initiatives and actions from all key Government departments and agencies are included in this strategy.

One of the fundamental cross cutting objectives of the strategy is to improve and establish 'mechanisms to ensure the participation of seldom-heard and vulnerable children and young people in decision-making'.[96] The accompanying Action Plan specifically commits the HSE Disability Services to develop a framework document on how children's voices will inform the design, implementation and evaluation of disability services. This is the only action specifically focused on children with disabilities. The most recent implementation report of the Action Plan documents this action as having been achieved, noting a subgroup was established in 2018 to progress the implementation of the HSE Outcomes-Focused Performance Management and Accountability Framework.[97] The 2013 HSE Outcomes-Focused Performance Management and Accountability Framework, intended to progress disability services for children and their families, identifies children and young people having a voice in all matters affecting them as the first intended outcome.[98] No further information is provided on how this outcome will be achieved and no evidence was uncovered of a framework specific to supporting children to inform the design, implementation and evaluation of disability services.

Tusla has developed an agency wide strategy with the focus on the participation of children and young people in decision-making as the key objective. One of the actions in the Tusla Child and Youth Participation Strategy 2019–2023, is to promote the DCYA 'Practical Guide to Including Seldom-heard Children and Young People in Decision-Making', to support the inclusion of children with disabilities.[99] Another action of the Tusla Strategy is to make seed funding available to support and encourage best-practice development in children and young people's participation, with a particular focus on seldom heard children, including children with disabilities.[100] Under the Tusla Prevention, Partnership and Family Support Programme, in 2016 Tusla implemented a seed funding for participatory practice initiative to support and progress participatory practices within the agency.[101]

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[95] Department of Children and Youth Affairs, *National Strategy on Children and Young People's Participation in Decision-making, 2015 – 2020* (Dublin, 2015).

[96] ibid 40.

[97] Department of Children and Youth Affairs, *Third Action Plan Update Of the National Strategy on Children and Young People's Participation in Decision-Making 2015–2020* (Dublin, 2018) (obtained following a request to the DCYA).

[98] Standards and Performance Reporting Working Group for Progressing Disability Services for Children and Young People programme, *Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams* (Dublin, 2013) 20.

[99] Tusla, *Child and Youth Participation Strategy 2019–2023* (Dublin, 2019) 24.

[100] ibid 28.

[101] Tusla, Seed Funding for Participatory Practice; A list of the projects funded in 2016/2017 is available at <https://www.tusla.ie/uploads/content/PPFS_Participatory_Practice_List_2016.pdf> accessed 13 October 2020.

Previously, in 2007, the then Office of the Minister for Children and Youth Affairs established the Inclusion Programme. This programme selected seven organisations working with marginalised or hard-to-reach young people across Ireland to support, through grant aid, young people's involvement in youth participation structures and processes.77 One of the organisations selected was a representative organisation for children with disabilities. Through the structures and processes, it was envisaged that these marginalised young people would be supported to engage with the County Councils', youth participation structures, Comhairle na nÓgs and any other Government funded structures that seek to hear the views of children and young people. An evaluation of the Inclusion Programme found that without a specific drive to include marginalised young people, they were unlikely to become involved in participatory structures, highlighting the ongoing need for investment in this area.

National standards also form part of the framework from within which children's services operate. The Health Information and Quality Authority (HIQA) has a statutory function to set standards on safety and quality. The HIQA National Standards for Residential Services for Children and Adults with Disabilities, require services to adhere to the key principles of rights, quality of life, person-centred, autonomy, equity and participation.[102] Standard 1.6 provides in detail the requirement that each child participates in decision making, has access to an advocate, and that consent is obtained in accordance with legislation and current best practice guidelines.[103] Participation also features in Standard 2.1 concerning a child's personal plan which details their needs and outlines the supports required. Review of the personal plan is multidisciplinary and to be conducted in a manner that ensures the maximum participation of children, their families, key worker and where appropriate, their representative (Standard 2.1.4).[104]

5.2.2 Key barriers to the realisation of rights

Limited Government Commitment and Resources Supporting Individual Children with Disabilities to Participate in Personal Plans

The legislative and policy framework supporting children with disabilities to participate in decisions directly affecting their lives is limited and weak on implementation. At the legislative level, there is no explicit constitutional or legislative protection for a child with disabilities to participate in personal planning related to their medical care. Existing legislative provisions relating to educational planning are limited and have yet to be commenced, as noted above. Despite this the National Council for Special Education (NCSE) has developed guidance on the preparation of Individual Education Plans (IEPs).[105] While the guidance suggests that a child, if appropriate, should be facilitated to participate in the planning process with the support of a sympathetic adult[106], it also goes on to suggest the child participate in the process only towards the end and by asking them to sign the final plan.[107] The UNCRC Committee noted in its concluding

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[102] Health Information and Quality Authority, *National Standards for Residential Services for Children and Adults with Disabilities* (Dublin, 2013) 8.

[103] ibid 23.

[104] ibid 26.

[105] National Council for Special Education, *Guidelines on the Individual Education Plan Process* (Dublin, 2006) <https://ncse.ie/wp-content/uploads/2014/10/final_report.pdf> accessed 3 April 2020.

[106] ibid 18.

[107] ibid, 55.

observations that the EPSEN Act has not been fully commenced and criticised the lack of a comprehensive strategy regarding the inclusion of children with disabilities in mainstream education or the promotion or encouragement of their autonomy.[108]

At the policy level, as set out above, the HSE Outcomes-Focused Performance Management and Accountability Framework, identifies children and young people with a disability having a voice in all matters affecting them as the first intended outcome.[109] The accompanying indicator to measure progress towards meeting this outcome is the percentage of children and young people who report that their voice is heard in matters which are important to them.[110] It appears that data relevant to this indicator has never been published and, as noted above, there is no detailed breakdown of measures to be taken to achieve this outcome. In a consultation with parents and children on the Framework, parents and children noted the language of this outcome was ambiguous and failed to take into account the preparation and support that needs to be provided to children, particularly children with cognitive and communication difficulties, to articulate their views.[111] The Action Plan accompanying the National Strategy on Children and Young People's Participation in Decision-making 2015–2020 has no actions specific to supporting the participation of children with disabilities in decisions directly affecting the individual child.

The research evidence available indicates that the limited Government commitment and resources available to support children with disabilities to participate in the development of personal plans, has implications for the realisation of the rights of children with disabilities in practice. Research was conducted on the participation of children with disabilities in their Individual Education Plan. A study, in 2016, which surveyed 83 Irish teachers found that pupils were unlikely to attend IEP preparation meetings.[112] Although they may not be present at these meetings, 28% of teachers in this study reported pupils are provided with an opportunity to express a view on their IEP, while 46% of teachers reported that pupils are only sometimes provided with such an opportunity. Similarly, earlier research found the participation of children with disabilities in Ireland in the development of IEPs to be the exception rather than the norm.[113]

Research has also been conducted on the participation of individual children in the development of child protection and welfare plans, when children require the services of Tusla, the National Child and Family Agency.[114] While not exclusively focused on

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[108] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3–4), para 47.

[109] HSE Standards and Performance Reporting Working Group for Progressing Disability Services for Children and Young People programme, *Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams* (Dublin, 2013) 20.

[110] ibid.

[111] HSE, *Progressing Disability Services for Children and Young People - Report on the Findings of Consultation on draft Outcomes Statements* (Dublin, 2013).

[112] Órla Ní Bhroin, Fiona King, Anita Prunty 'Teachers' Knowledge and Practice Relating to the Individual Education Plan and Learning Outcomes for Pupils with Special Educational Needs (2016) 22(9) Special Needs Education 78.

[113] Richard Rose, Michael Shevlin, Eileen Winter, Paul O'Raw and Yu Zhao, 'Individual Education Plans in the Republic of Ireland: an emerging system' (2012) 39(3) British Journal of Special Education 110.

[114] Edel Tierney, Danielle Kennan, Cormac Forkan, Bernadine Brady and Rebecca Jackson, *Children's Participation Work Package Final Report: Tusla's Programme for Prevention, Partnership and Family Support* (UNESCO Child and Family Research Centre, National University of Ireland Galway 2018).

children with disabilities, this research found that Tusla practitioners were experiencing difficulties consulting with harder-to-reach children and young people, including children with disabilities. Disability was a prominent feature presenting challenges to involving children and young people in decision-making. Although there was evidence of Tusla putting measures in place to support the participation of children with disabilities in their care plans (for example opportunities for staff to learn sign language), some local Tusla service areas still lacked resources for children with communication and sensory difficulties to adequately have their voice heard.[115] The research reiterated a consistent finding in the HIQA child protection and welfare and alternative care inspection reports that services need access to a loop system and for information to be provided in Braille, to support the participation of children with audio and visual disabilities.[116] This research also established, following a survey of Tusla staff in 2017, that skills to engage seldom-heard children and young people and skills to communicate creatively were the top two skills development needs identified by the staff.[117]

Children's Participation Structures and Processes are not Adequately Supporting the Voice of Children with Disabilities to be Collectively Heard in Public Decision-Making

In 2014, a review of the literature was conducted focusing on formal participation structures and initiatives that directly engage and support seldom heard young people to have a voice in the design, delivery and monitoring of policies and services that affect their lives and the experiences of young people within such processes.[118] This report identified children with disabilities in Ireland as 'seldom heard'. It found that 'existing participation structures, organisations and services that target their needs are not adequately enabling the voice of these young people to be heard'.[119] Findings suggested that children with disabilities belong to a group difficult to reach, both for youth organisations as well as the HSE and HSE funded services.[120] The review found that personal and practical issues potentially act as barriers to the inclusion of seldom heard young people in formal participation structures. This may be due to lack of confidence and skills necessary but also inaccessibility.[121] Similar findings were recorded in 2015, in a DCYA commissioned review of young people's involvement in youth participation structures and processes 97. This study found that, while organisations were generally able to combat physical barriers to inclusion in participation structures by finding suitable venues, young people's lack of confidence as well as discomfort proved to be challenging.[122]

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[115] The secondary analysis of HIQA inspection reports included all inspection reports of Foster Care Services, Child Protection and Welfare, Special Care Units, and Children's Residential Centres during the period 2013–2018.

[116] Edel Tierney, Danielle Kennan, Cormac Forkan, Bernadine Brady and Rebecca Jackson, *Children's Participation Work Package Final Report: Tusla's Programme for Prevention, Partnership and Family Support* (UNESCO Child and Family Research Centre, National University of Ireland Galway 2018) 44.

[117] ibid 34.

[118] Cathy Kelleher, Mairead Seymour and Ann Marie Halpenny 'Promoting the Participation of Seldom Heard Young People: A Review of the Literature on Best Practice Principles' (Dublin: Centre for Social & Educational Research, Dublin Institute of Technology, 2014).

[119] ibid 1.

[120] ibid 3.

[121] ibid 32.

[122] ibid 80.

Transforming Lives, which emerged in 2014, refers to the process of reform of HSE funded Disability Services in Ireland. Working Group 3 is one of six working groups set up by the HSE with responsibility for examining how people with disabilities and their families could be more involved in making decisions about services that affect their lives. In 2018, this group produced the plan Effective Participation in Decision-Making: Planning for Ordinary Lives in Ordinary Places.[123] While not specifically focused on children, its 2018 report documents some key barriers to effective participation in decision making for people with disabilities. They identified physical barriers in terms of inaccessible transport, buildings and facilities as an obstacle to participation. They also identified inaccessible information and how meetings are structured and organised as obstacles. Lastly, similar to above, they found that confidence and a lack of motivation, if previous experiences of participation have not resulted in change, can present barriers to participation. The HSE Plan also states that '[l]ow expectations in relation to a person's capacity to engage in debate and discussion present a significant obstacle in decision-making processes'.[124] The Plan identifies the need for a significant change in attitudes to pave the path for more effective participation in decision making processes.[125]

Exclusion of Children with Disabilities in Consultation and Monitoring Mechanisms

As referred to above, Articles 4 and 33 of the UNCRPD require States Parties to 'closely consult and actively involve persons with disabilities, including children with disabilities', in the development and implementation of legislation and policies concerning people with disabilities. The Department of Justice and Equality has established a Disability Participation and Consultation Network for engaging with people with disabilities in the development of policy and legislation.[126] The purpose of the network is to:

- establish mechanisms that can be used by Government departments and public agencies when consulting people with disabilities.
- undertake capacity building of disability representatives so that they can represent the voice of people with disabilities in diverse policymaking fora.
- provide support for people with disabilities participating in policy consultation or development processes.
- to establish systems for feedback to people with disabilities on issues raised by the disability representatives in policy fora.[127]

It is envisaged that the first task of the network will be to organise consultations for Ireland's first state report to the UN Committee on the Rights of Person's with Disabilities.[128] The network is made up of an Organising member (Inclusion Ireland), four Grant-funded Members (DPO Coalition, As I Am, Mental Health Reform and Disability

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123 HSE, *Transforming lives: Programme to implement the recommendations of the 'Value for money and policy review of disability services in Ireland' Effective participation in decision making: Planning for ordinary lives in ordinary places* (Dublin, 2018) 12–13.

124 ibid 12.

125 ibid 22.

126 Department of Justice and Equality, *Mid-Term Review of the National Disability Inclusion Strategy 2017–2021* (Dublin, 2020) 14-15.

127 Department of Justice and Equality, *Mid-Term Review of the National Disability Inclusion Strategy 2017–2021* (Dublin, 2020) 38.

128 Department of Justice and Equality, Launch of Expressions of Interest to establish a Disability Participation and Consultation Network <https://www.gov.ie/en/press-release/a4ea9-launch-of-expressions-of-interest-to-establish-a-disability-participation-and-consultation-network/> accessed 10 October 2020.

Federation Ireland) and over 70 voluntary members.[129] As it is still early in the network's operation, it is currently unclear how the model will ensure meaningful participation of children with disabilities in policymaking fora. The current mechanism for monitoring the implementation of the NDIS comprises no individuals or organisations whose specific remit is to represent children with disabilities. Ireland is also obligated under article 33 of the UNCRPD to establish an independent mechanism to monitor the implementation of the Convention. The Irish Human Rights and Equality Commission is the monitoring mechanism in Ireland. In compliance with the requirement that people with disabilities must be part of the monitoring process, the Commission has established a Disability Advisory Committee. There are no child representatives on this Committee.

5.2.3 Measures to overcome identified barriers

Legislative Measures

Steps need to be taken to address the lacuna in the law and protect in legislation the right of children with disabilities to have their views heard all contexts. As a first step, the provisions in the EPSEN Act 2004, on a child's participation in educational and transition planning,[130] need to come into force. The high level of discretion the Act affords to teachers and special educational co-ordinators regarding a child's participation can be addressed by improved and stronger guidance on the preparation of IEPs. Legislative measures also ned to be taken to address the absence of a clear legal framework in Ireland governing a child's, including children with disabilities', consent to or refusal of medical treatment.

Administrative and Other Measures

Training, capacity building, resource allocation and other measures

Staff training, clarity on what the term 'involvement' or 'participation' means and how it can be achieved, are some of the measures identified in the literature to overcome barriers to children with disabilities having their views heard.[131] The Effective Participation in Decision Making: Planning for Ordinary Lives in Ordinary Places HSE report also identified a range of measures required, these being:[132]

- Changing and challenging attitudes;
- Valuing the knowledge and experience of persons with disabilities;
- Improving communication;
- Improving accessibility;
- Structuring and organising meetings better to support the participation of persons with disabilities.

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[129] MerrionStreet.ie, Minister Rabbitte hosts first meeting with Disability Participation and Consultation Network <https://merrionstreet.ie/en/news-room/news/minister_rabbitte_hosts_first_meeting_with_disability_participation_and_consultation_network.166404.shortcut.html> accessed 25 January 2021.

[130] Education for Persons with Special Educational Needs Act 2004, s8(4)(a) and s15(2)(a).

[131] Emer Bergin and Anna Logan, 'An individual education plan for pupils with special educational needs: How inclusive is the process for the pupil?' (2013) 26 (2) Reach 79.

[132] HSE, *Transforming lives: Programme to implement the recommendations of the 'Value for money and policy review of disability services in Ireland' Effective participation in decision making: Planning for ordinary lives in ordinary places* (Dublin, 2018) 21-27.

A toolkit was developed in 2015 by the DCYA and Barnardos, with input from the National Disability Authority (NDA), as a practical guide to support practitioners to include seldom-heard children and young people in decision-making.[133] This toolkit advised that the inclusion of seldom-heard children and young people's needs to be 'embedded in the culture and structure of an organisation if it is to result in their increased and meaningful participation. It does take time, resources and concerted effort from management or it simply will not happen. It is best to adopt a whole systems approach and framework to ensure the effective participation of seldom-heard children and young people'.[134]

Understanding that to embed a culture of participation requires a multi-faceted and whole systems approach, in 2015, Tusla as part of the Programme for Prevention, Partnership and Family Support funded by The Atlantic Philanthropies, initiated a programme of action to embed the practice of children's participation within child protection and welfare services. This programme of action comprised: the development and dissemination of the Tusla National Child and Youth Participation Strategy and a National Children and Young People's Charter; the development and delivery of child and youth participation training to all staff, accompanied by the development of a participation toolkit for practitioners; the development of a quality assurance framework to ensure participatory practice was compliant with article 12 of the UNCRC; a seed funding initiative to support innovative participatory practices; awareness raising; the establishment of participation structures to support children in foster care to influence policy development and service provision; and the development of a child friendly complaints service.[135]

An evaluation of this programme of action to assess the extent to which it facilitated the participation of children becoming embedded in Tusla culture and operations found that there was strong evidence of children's participation being embedded within the Agency following the implementation of this programme of action.[136] Notably, agency wide competency-based participation training for staff and an accompanying toolkit had a significant impact on staff perceptions of their own capacity to support the participation of children. The evaluation findings indicate that these measures are effective in supporting the implementation of a child's right to have their views heard. Resourcing and implementing a similar child and youth participation programme of action within children's disability services could result in similar outcomes and advance the right of children with disabilities to be heard.

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[133] Department of Children and Youth Affairs, *A practical guide to including seldom-heard children & young people in decision-making* (Dublin, 2015).

[134] ibid 16.

[135] For more information on this Programme of Action see Edel Tierney, Danielle Kennan, Cormac Forkan, Bernadine Brady and Rebecca Jackson, *Children's Participation Work Package Final Report: Tusla's Programme for Prevention, Partnership and Family Support* (UNESCO Child and Family Research Centre, National University of Ireland Galway 2018).

[136] ibid.

Advocacy services

Previous research has found that the use of advocates is an effective means of supporting children, including children with disabilities, to have their views heard.[137] Advocacy in this context has been defined as 'the provision of one to one support by an individual or a service for the purpose of enabling a child to have their voice heard'.[138] Children have consistently testified to the value of having an advocate. Research with children who had learning difficulties and mental health issues found advocates to be instrumental in supporting the children to have their views listened to in decisions about their lives.[139] The National Advocacy Service provides a free and confidential advocacy service to adults with a disability in Ireland. However, there is no such service for children with disabilities in Ireland. To effectively support children with disabilities to have their views heard there is a need for children with disabilities to have access to an independent advocacy service to support them.

5.3 Accessibility

Access is essential for persons with disabilities to participate fully and equally in society.[140] In this instance access does not solely refer to making buildings or the physical environment accessible but rather to full and equal access to all aspects of society,[141] including information and communications technologies and systems, and to other facilities and services open or provided to the public.[142]

Accessibility is a core principle of the UNCRPD and as a result States Parties have wide ranging obligations in that regard.[143] Their obligations include providing information in an accessible manner, promoting the development of universally designed goods and new technologies, ensuring access to the built environment, transport and ICT and the identification and elimination of barriers.[144] The UNCRPD Committee has clarified that States Parties' obligations regarding accessibility are 'an *ex ante* duty' which require infrastructure, information, goods, services etc. to be accessible without relying on an individual to first request access.[145] In contrast, the duty to reasonably accommodate persons with disabilities is 'an *ex nunc* duty' which is only enforceable when a person with a disability requests access and only if it does not amount to an undue burden on the entity who would provide it.[146] This distinction also means that while a denial of reasonable accommodation amounts to discrimination, the failure to provide accessibility is not considered a form of disability-based discrimination. The UNCRPD

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[137] Danielle Kennan, Bernadine Brady and Cormac Forkan, 'Supporting Children's Participation in Decision Making: A Systematic Literature Review Exploring the Effectiveness of Participatory Processes' (2018) 48(7) The British Journal of Social Work,1990.

[138] ibid 1994.

[139] Abigail Knight and Chris Oliver, 'Advocacy for disabled children and young people: Benefits and dilemmas' (2007) 12(4) Child and Family Social Work, 417.

[140] UN Committee on the Rights of Persons with Disabilities, General Comment No. 2 (2014) Article 9: Accessibility (CRPD/C/GC/2), para 1.

[141] Commission on the Status of People with Disabilities, *A Strategy for Equality: Report of the Commission on the Status of People with Disabilities* (Dublin, 1996) 33.

[142] UN Committee on the Rights of Persons with Disabilities, General Comment No. 2 (2014) Article 9: Accessibility (CRPD/C/GC/2), para 1.

[143] UNCRPD, art 3(f).

[144] UNCRPD, art 4 and art 9.

[145] UN Committee on the Rights of Persons with Disabilities, General Comment No. 2 (2014) Article 9: Accessibility (CRPD/C/GC/2), para 25.

[146] ibid para 26.

also places an obligation on States to promote universal design of ‘goods, services, equipment and facilities’.[147] The UNCRC also recognises that children with disabilities have the right to enjoy a full and decent life and that States Parties should facilitate their involvement in the community,[148] which includes accessibility measures for children with disabilities.[149]

5.3.1 Current Irish Context: Overview of law and policy

In Irish law, the accessibility of public buildings and services for disabled persons is provided for in the Disability Act 2005. Under the Act public buildings must be ‘as far as practicable’ accessible to persons with disabilities.[150] In practice this required public buildings to be renovated, where necessary, in line with Part M of the Building Regulations by December 2015 unless the use of the building was temporary or the cost of the alterations could not be justified.[151] The Act also requires disabled persons to have access to public services ‘where practicable and appropriate’.[152] This requires public services to be available to persons with disabilities at the same point of access, time or location as non-disabled persons.[153]

Disabled persons should also be supported to access public services ‘where practicable and appropriate’.[154] Public bodies are required to designate an ‘access officer’ to oversee and ensure access to its services by persons with disabilities and ensure they consult with someone with the appropriate skills and expertise regarding accessibility.[155] Part 3 of the Disability Act also requires government departments to plan for how they would provide services to persons with disabilities.[156] The NDA has developed a Code of Practice[157] an Accessibility Toolkit[158] and Guidelines for Access Auditing[159] to guide public bodies in meeting their statutory obligations. However, they do not specifically address the additional barriers children with disabilities may face.

Public bodies must ‘do all that is reasonable’ to provide sign language interpretation for persons with disabilities to access statutory entitlements or services under the Irish Sign Language Act, when commenced.[160] This may be via a remote or online

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[147] UNCRPD, art 4(f).

[148] UNCRC, art 23.

[149] See for example UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic report of Austria 2012 CRC/C/AUT/CO/3–4 para 44 and 45; UN Committee on the Rights the Child, Concluding observations on the combined fifth and sixth periodic reports of Costa Rica 2020 CRC/C/CRI/CO/5–6 para 35.

[150] Disability Act 2005, s25.

[151] ibid.

[152] ibid, s26.

[153] National Disability Authority, *Code of Practice on Accessibility of Public Services and Information provided by Public Bodies* (2006) 12.

[154] Disability Act 2005, s26.

[155] ibid.

[156] ibid, s31.

[157] National Disability Authority, *Code of Practice on Accessibility of Public Services and Information provided by Public Bodies* (Dublin, 2006) 3.

[158] National Disability Authority, *Accessibility toolkit* (Dublin, 2012) <http://nda.ie/Resources/Accessibility-toolkit/> accessed 4 June 2020.

[159] National Disability Authority, *Guidelines for Access Auditing of the Built Environment* (Dublin, 2012) <http://nda.ie/Publications/Environment-Housing/Environment-Publications/Guidelines-for-Access-Auditing-of-the-Built-Environment.html> accessed 26 August 2020.

[160] Irish Sign Language Act 2017, s6.

interpreting service and must be free of charge to the disabled person.[161] The Act, when commenced, will also allow a person to use Irish Sign Language in court and for the court to employ interpreters to ensure the person is not placed at a disadvantage.[162]

The Building Regulations 2010 have specific measures which aim to make both public and private buildings accessible and useable by persons with disabilities.[163] The regulations impose a range of obligations dependant on whether it is a new build, an extension and whether it is intended to be a dwelling.[164] They require buildings to be designed so persons with disabilities can access and use a building safely and independently. This is limited however to what is 'practicable' and therefore would not require a building with historical significance to be accessible, for example.[165] Further, new dwellings need only be visitable by persons with disabilities.[166]

The National Disability Inclusion Strategy 2017 – 2021 has identified a number of key actions which relate to accessibility. [167] The strategy mirrors many elements of the Disability Act in relation to public sector information and services, including bringing public sector buildings in compliance with Part M by 2022, reviewing the effectiveness of the 2005 Act and making public transport accessible.[168] A review by the NDA published in 2019 notes that while some progress has been made, there is a need for further focus to ensure the accessibility of public services, including public buildings and websites.[169] Furthermore, Ireland was required to transpose the EU Web Accessibility Directive[170] into domestic law by July 2018, however, at the time of writing this has not been achieved.[171]

5.3.2 Key barriers to the realisation of rights

Lack of clarity and consistency regarding the accessibility of public services and buildings

Public buildings in Ireland have an 'inconsistent level of accessibility' and, therefore, children with disabilities may not be aware which buildings are accessible or what accessibility measures have been put in place. [172] This may be due to the number of qualifications placed on the duty under legislation, as noted above, a lack of

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[161] ibid.

[162] ibid s4.

[163] Department of Environment, Heritage and Local Government, *Building Regulations 2010: Technical Guidance Document M Access and Use* (Dublin, 2010).

[164] ibid 9.

[165] ibid.

[166] ibid 10.

[167] Department of Justice and Equality, *National Disability Inclusion Strategy 2017–2021* (Dublin, 2017).

[168] ibid.

[169] National Disability Authority, *Independent assessment of progress under NDIS 2017–2018* (Dublin, 2019) <http://nda.ie/Publications/Justice-and-Safeguarding/National-Disability-Inclusion-Strategy/NDA-independent-assessment-of-NDIS-2017-20181.pdf> accessed 4 June 2020.

[170] Directive (EU) 2016/2102 of the European Parliament and of the Council of 26 October 2016 on the accessibility of the websites and mobile applications of public sector bodies OJ L 327/1.

[171] Department of Communications, Climate Action and Environment, Web Accessibility <https://www.dccae.gov.ie/en-ie/communications/topics/Digital-Strategy/web-accessibility/Pages/Web-Accessibility.aspx> accessed 1 September 2020.

[172] National Disability Authority and the Office of Public Works, *An Operational Review of the Effectiveness of Section 25 of the Disability Act* (Dublin, 2019) <http://nda.ie/Publications/Environment-Housing/Environment-Publications/Operational-Review-of-the-Effectiveness-of-Section-25-of-the-Disability-Act-20051.pdf> accessed 27 August 2020.

understanding by local authorities or public bodies of the duties imposed, or the lack of sanctions on public bodies who do not comply with the Act.[173] A lack of funding to support compliance with the updated Part M regulations has also been noted by public body representatives.[174]

Limited duties placed on the private sector

Another key barrier regarding accessibility comes from the limited obligations placed on the private sector. Part M of the Building Regulations apply to both public and private buildings, however there is little information or guidance on their application in private sector or the adherence therein. The private sector also has limited obligations regarding the accessibility of services or information and may rely on the same limitations or qualifications, noted above, which apply to the public sector. Limited complaint mechanisms and sanctions may significantly impact compliance rates also.

Restricted access to public information

A study completed by the Citizen Information Board in 2017, identified a number of barriers faced by the Deaf Community in accessing public information in Irish Sign Language.[175] Among those barriers was a lack of awareness among public officials of the specific needs of Deaf people in comparison to persons who are Hard of Hearing, insufficient training in disability awareness and in Deaf awareness.[176] The study also noted 'a large gulf' between the policy statements made by public organisations in relation to providing sign language interpreters and what is available through frontline services.[177] Key pieces of legislation which would address these issues, such as the Irish Sign Language Act 2017, have not been commenced and therefore have no legal force.

Subsequently, research examining section 25 of the 2005 Act has found that information on building accessibility, including wayfinding information, is not often available to persons with disabilities or available in a range of accessible formats.[178]

5.3.3 Measures to overcome identified barriers

Legislative Measures

The Irish Sign Language Act 2017 must be commenced to ensure accessibility for the Deaf children across public services. Research conducted into the efficacy of the Disability Act 2005 concluded that amending the legislation to provide for stronger complaints mechanisms and a better equipped building regulation inspectorate would increase compliance. [179]

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[173] ibid.

[174] ibid

[175] Citizens Information Board, *Information provision and access to public and social services for the Deaf Community* (Dublin, 2017) 4.

[176] ibid 4.

[177] ibid 5.

[178] National Disability Authority and the Office of Public Works, *An Operational Review of the Effectiveness of Section 25 of the Disability Act* (Dublin, 2019) <http://nda.ie/Publications/Environment-Housing/Environment-Publications/Operational-Review-of-the-Effectiveness-of-Section-25-of-the-Disability-Act-20051.pdf> accessed 27 August 2020.

[179] ibid.

Administrative and Other Measures

Funding and budgets

Funding must be made available to ensure adequate availability of sign language interpreters and others supports.[180] This includes funding to support the training of new interpreters to address the shortage of people qualified in this area. Additional funding should also be provided to ensure public bodies can make subtitles or captioning available on any videos published and have the resources to provide communication methods which are accessible to Deaf or hard of hearing children, such as 'chat facilities', on their websites.[181] Funding must also be made available to support public bodies to renovate buildings in line with the updated Part M Building regulations.

Training and awareness raising

Research on the efficacy of the 2005 Act noted that many public bodies are not sufficiently aware or supported to comply with the updated requirements under Part M of the Building Regulations 2010 by January 2022.[182] To address this the relevant Departments or bodies must raise awareness through training programmes, and informational campaigns on what constitutes a public building, universal design principles and the level of accessibility required across disability or impairment types.

Private sector duties must be clarified and clear information provided for those working in the sector regarding accessibility across age and impairment types. This could include information campaigns or resources for employers, service providers and building owners regarding their duties, consultation procedures and supports, including financial supports available. In Austria an online self-check tool is available to companies to increase their understanding of and assess their compliance with the legislative requirements.[183]

Disability and Deaf awareness training must also be provided to staff working in public services or to those providing public information to ensure an increased understanding of the accessibility needs of children with disabilities.[184] Information must also be made available to the public, including in forms accessible to children with disabilities, on the legal duties placed on the private sector and what complaints mechanisms are available to them for incidents of non-compliance. Persons with disabilities, including children with disabilities, should be involved in the design and delivery of all such initiatives in line with the UNCRPD and international best practice.[185]

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[180] Citizens Information Board, *Information provision and access to public and social services for the Deaf Community* (Dublin, 2017).

[181] ibid, 114.

[182] ibid

[183] Zero Project, 'Online accessibility self-check tool for companies' (Vienna, 2018) <https://zeroproject.org/practice/pra181120aut-factsheet/> accessed 27 August 2020.

[184] ibid

[185] UN Committee on the Rights of Persons with Disabilities, General Comment No. 7 (2018): The participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention (CRPD/C/GC/7) 1.

Participation and consultation

Users consulted in National Disability Authority research highlighted that buildings should not be renovated or designed to comply with a minimum standard but rather in line with Universal Design principles which should capture the needs of a range of societal groups including children with disabilities.[186] In doing so public bodies should consult widely with potential end users including through 'Walkability' audits. It is essential that children with disabilities are included in these processes as individuals where possible and not only as represented by their parents or others.

Transparency and advance information

A lack of transparency regarding levels of accessibility and what measures or supports are in place can be addressed using detailed information freely available on the relevant website or signage. This should include wayfinding information and information on accessibility for a range of impairments or age cohorts, including children with disabilities, and contact details for the designated access officer in accessible formats.

A building accessibility rating system has been put in place in Germany, the Netherlands, Turkey and Belgium by EUKOBA based on the commonly used colour coded energy efficiency rating system.[187] BPASS assess the accessibility of public spaces using a 300 question checklist and rates the space from A to G across a range of age and disability or impairment types, including specifically for children and young people.[188] The building owner or local authority also receives recommendations to improve access as a result of the survey. This approach would provide clear, accessible and comprehensive information to all users of a building or service and increase understanding of barriers across age and disability or impairment types.

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[186] National Disability Authority and the Office of Public Works, An Operational Review of the Effectiveness of Section 25 of the Disability Act (2019) <http://nda.ie/Publications/Environment-Housing/Environment-Publications/Operational-Review-of-the-Effectiveness-of-Section-25-of-the-Disability-Act-20051.pdf> accessed 27 August 2020.

[187] European Competence Center for Accessibility eV, 'BPASS® accessibility measurable for everyone' <https://www.bpass.eu/> accessed 27 August 2020.

[188] Zero Project, 'Innovative Practice 2018 on Accessibility - Rating the accessibility of buildings using a well-known seal system' <https://zeroproject.org/practice/pra181160ger-factsheet/> accessed 27 August 2020.

6. Cluster 1 – Development

6.1 Education

According to the UNCRC, articles 28 and 29, every child has the right to access education and to be educated. That education should ideally be held in an inclusive setting.[189] The aim of the right to education goes beyond academic achievement to the development of the child's personality, talents and abilities to their fullest potential, and to providing them with the tools to live a full and responsible life within society.[190] Further, article 23 provides specific detail in relation to the State's obligations towards disabled children, a number of which are highly relevant in the context of education. These include the facilitation of the child's active participation in the community and the right of the disabled child to special care. Article 23(3) places a duty on the State to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child achieving the fullest possible social integration and individual development.[191] The right to education also features in the UNCRPD, where article 24 provides that 'States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning.'[192]

6.1.1 Current Irish Context

6.1.1.1 Profile of children with disabilities

While it is difficult to ascertain exactly how many children with disabilities are in the Irish education system, statistics are available on the number of children receiving special educational needs support in a range of different settings. According to figures from 2016 (the latest year for which such statistics are available), there were 181,218 students with special needs in primary and post-primary education in Ireland (comprising 20% of the total number of students).[193] However, the *Growing Up in Ireland* report suggests that the figure is 25%.[194] The majority of children with disabilities in Ireland are receiving their education in mainstream schools, mostly with supports such as special educational needs assistants in mainstream classrooms.

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[189] UN Committee on the Rights of the Child, General Comment No. 9 (2006): The Rights of Children with Disabilities (CRC/C/GC/9) para 66.

[190] Children's Rights Alliance, 'Report Card 2020' (Dublin, 2020) 11.

[191] Conor O'Mahony, 'Education, play and leisure' in Children's Rights Alliance and Law Centre for Children and Young People, *Making Rights Real for Children: A Children's Rights Audit of Irish Law* (Dublin, 2015) 132-133.

[192] UNCRPD, art 24.

[193] Irish Government Economic and Evaluation Service, *Focused Policy Assessment of Data on Special Needs Assistants* (Department of Education and Skills, 2016) 15.

[194] Selina McCoy, Joanne Banks & Michael Shevlin, 'Insights into the Prevalence of Special Educational Needs' in James Williams, Elizabeth Nixon, Emer Smyth & Dorothy Watson (eds) *Cherishing All the Children Equally? Ireland 100 years on from the Easter Rising* (2016) 157.

There is however a noticeable trend towards the provision of special classes within mainstream education. For example in 2012/2013 there were just over 600 special classes, by 2020 that figure has increased to over 1600 such classes.[195] Many of these classes are classes specifically for children with autism. Banks highlights that in 2001 there were just 39 autism units by 2014 that had increased to 627, and these classes account for much of the increase in special classes.[196]

In 2016, 113,888 children with special educational needs were being catered for under the 'general allocation model' meaning those in mainstream classrooms.[197] An analysis of support needs from 2011-2016 found that the numbers of students accessing support in special classes in mainstream increased by 67%, the largest percentage increase of all the cohorts, from 3,286 to 5,472, and those attending special schools increased by 9% from 7,420 to 8,092.[198]

6.1.1.2 Overview of law and policy

Article 42 of the Irish Constitution provides for a right to education. The article imposes a duty on the State to 'provide for free primary education.' There is no explicit right to receive education within the Constitution, it has been interpreted as creating a right for children to receive an education.[199] It has been held that the State must provide education for children with disabilities 'in as full and positive a manner as it has done for all other children in the community.'[200] Additionally, the Constitution provides at article 42.3.2 that the State, as guardian of the common good will ensure that children receive a certain minimum education.

The Education Act, 1998 elaborates on article 42.4 of the Constitution by providing in Section 7 that it is a function of the Minister for Education to ensure that a level and quality of education appropriate to meeting the needs and abilities of persons are made available to each person resident in the State; to provide funding and support services to schools to this end; and to monitor and assess the quality, economy, efficiency and effectiveness of the education system provided in the State.[201]

While article 42.4 of the Irish Constitution makes it clear that the State has a duty to provide for free primary education, it does not explicitly refer to any other level of education. Article 42.4 does, however, provide that the State 'shall endeavour to supplement and give reasonable aid to private and corporate educational initiative, and, when the public good requires it, provide other educational facilities or institutions'. In practice, the vast majority of schools are privately owned but publicly funded.[202] State-funded education is available at primary, second level, further education and third-level education. Section 7 of the Education Act, 1998 applies equally to primary and post-primary education and the Education (Welfare) Act, 2000 provides for compulsory

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[195] Joanne Banks, 'Examining the Cost of Special Education' in Umesh Sharma (ed), *Inclusive and Special Education* (Oxford University Press, forthcoming).

[196] ibid.

[197] ibid.

[198] ibid.

[199] *Crowley v Ireland*, [1980] 1 IR 122.

[200] *O'Donoghue v. Minister for Health* [1993] IEHC 2; [1996] 2 IR 20.

[201] Conor O'Mahony, 'Education, play and leisure' in Children's Rights Alliance and Law Centre for Children and Young People, *Making Rights Real for Children: A Children's Rights Audit of Irish Law* (Dublin, 2015) 136.

[202] Constitution Review Group, *Report of the Constitution Review Group* (Dublin 1996) 316.

education up to the age of 16.The Constitution Review Group recommended that article 42.4 should be extended to expressly encompass second level education as it would reflect not only the practical reality, but also strengthen the educational rights of children under the Constitution, which is in line with the UNCRC's target of progressive realisation of the right to free post primary education.[203]

Disability and Special Educational Needs

Section 7 of the Education Act, 1998 expressly states that the duty of the Minister for Education to make appropriate education available to everyone in the State includes persons with a disability or who have other special educational needs. The Education for Persons with Special Educational Needs (EPSEN) Act 2004, establishes a comprehensive framework for the assessment of educational needs; the drafting of education plans that set out the educational provision to be made for children, and create a legal entitlement to the services specified therein; periodic reviews of these education plans; and an accessible specialised appeals process to adjudicate on disputes.[204] However, the main provisions of this Act have not been commenced and so it is not legally enforceable for persons with special educational needs.

The EPSEN Act 2004, though not commenced, makes provision for children up to 18 years of age and ensures that parents have adequate opportunity to express their views at each point in the process. However, less emphasis is placed on ensuring that children are in a position to independently express their views and actively participate in the various stages of the process. The major exception in this regard is the preparation of education plans: Section 8(4) of the Act provides that where the National Council for Special Education (NCSE) is preparing an education plan for a child, the relevant special educational needs organiser shall convene a team of people to provide advice to them in relation to the preparation of the education plan, and that team of people shall include the child, where this is considered appropriate by the special educational needs organiser having regard to the age of the child and the nature and extent of the child's special educational needs. Unfortunately, no comparable provision exists in Section 3, which deals with education plans that are prepared within the school and cater for children with less complex special educational needs.

Regarding other stages of the process, no provision is made in the Act for children to be active participants in assessments of educational needs, although any proper assessment of educational needs would have to afford a child the opportunity to express their views about their educational needs. Section 11, which refers to the periodic reviews of education plans, allows parents to request a review but does not provide for the participation of children in reviews. The same approach is taken to appeals to the Special Education Appeals Board established under the Act. The lack of provision for children to participate is clearly out of line with article 12 of the UNCRC, and while the terms of article 42A do not apply to administrative proceedings such as the Special Education Appeals Board, the exclusion of children from the process is nevertheless inconsistent with the spirit of the constitutional amendment.[205]

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[203] ibid 332.

[204] Conor O'Mahony, 'Education, play and leisure' in Children's Rights Alliance and Law Centre for Children and Young People, *Making Rights Real for Children: A Children's Rights Audit of Irish Law* (Dublin, 2015) 138.

[205] ibid.

Early Years

2016 saw the introduction of the Access and Inclusion Model (AIM) to facilitate easier access to the Early Childhood Care and Education (ECCE) scheme for children with disabilities. AIM is a child-centred model, involving seven levels of progressive support, moving from the universal to the targeted, depending on the needs of the child and the pre-school. Additionally, a range of different initiatives such as guideline training, a new higher education programme for early years practitioners and a national specialist service for pre-school providers were launched as part of the model.[206] AIM is a child-centred model that has various levels of support from general supports to individually targeted supports for children with more complex needs. Inclusion Ireland raise the concern that these supports are only available to a child attending the limited ECCE scheme i.e. 15 hours per week and for a total of 38 weeks per year over two years. For the rest of their early year's engagement, the child will have no supports in place unless privately funded.[207]

Primary and secondary education

There has been significant growth in the number of children with special needs attending mainstream schools, and as a result, the increase in resources over recent years has been welcome. However, this growth has been in segregated autism units, which is not in line with the principle of inclusive education. Despite the increased allocation of resources, some special schools are oversubscribed, hundreds of children are on waiting lists for special classes in mainstream schools and in many cases, the only place that parents can find may be far outside the local school-catchment area. The latter issue results in a significant number of children being educated at home with the support of home tuition grants, meaning, they are missing out on the key social development elements of being in an educational setting.[208]

There is also evidence to suggest that the transition from primary to secondary education is particularly difficult for children with disabilities.[209] The Education (Admission to Schools) Act 2018, commenced in 2020, and it requires schools to explicitly state that they will not discriminate because of disability as well as some other protected grounds. In addition, section 8 provides for an additional section (s 37a) to be inserted into the Education Act 1998, enabling the Minister for Education and Skills to compel a school to make provision for the education of children with special educational needs if a consultation between the NCSE, the school's board of management, and the school's patron, has not resulted in the school providing the places required.[210]

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[206] Government of Ireland, 'Press Release: Better Pre-School Access for Children with Disabilities 'Access and Inclusion Model: AIM' unveiled Minister Zappone urges Parents to apply' (2016) <http://aim.gov.ie/wp-content/uploads/2016/06/Press-Release-15-June-2016.pdf> accessed 17 April 2020.

[207] Inclusion Ireland, 'Pre-Budget submission 2020 - Inclusion Ireland' <http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1651/budget-2020-full-submission-final.pdf> accessed 10 April 2020.

[208] Children's Rights Alliance, 'Report Card 2020' (Dublin, 2020) 27-28.

[209] Yvonne Barnes-Holmes et al. *'A Study of Transition from Primary to Post-primary School for Pupils with Special Educational Needs'* (National Council for Special Education, 2013); The NCSE has developed information supports for educational transitions, see <https://www.sess.ie/resources/transitions> accessed 17 April 2020.

[210] Children's Rights Alliance, 'Report Card 2020' (Dublin, 2020) 28; Education (Admission to Schools) Act 2018, s8.

A system for the allocation of resources for special education provision in mainstream primary and post-primary schools was introduced in 2017 with allocations now being based on a profile of the needs of each school, without the requirement for a diagnosis of disability for individual children in the school.[211] The system is intended to provide a greater degree of autonomy for schools in determining how resources are used, but it does not adequately address the difficulties that arise where parents and the school in which their child is a pupil disagree about the support allocated to the child. Parents can no longer appeal resource decisions to the NCSE, whereas previously the appeals process led to a number of allocation decisions being overturned.[212] Instead, a discussion of issues with the class teacher and school principal is now recommended by the Department of Education and Skills when a parent is concerned about the level of support provided for their child. If the response is not satisfactory, the matter should be raised with the school's Board of Management. The reliance on local level appeals would appear to mitigate against a consistent approach to resolve such concerns. Guidance documents have been published to inform parents of the system and associated processes, however, the absence of any form of independent appeal mechanism places parents in a vulnerable position.[213]

Many children with special educational needs may need reasonable accommodations to ensure that they can fully avail of and participate in education. The duty to provide reasonable accommodation is legally provided for and all education bodies are subject to this provision.[214] More significant supports are provided through the offices of the NCSE, such as the provision of SNAs.[215] These additional supports are not based on law, but policy, as the EPSEN Act has yet to be commenced.

A review of the SNA Scheme by the NCSE in 2018 concluded that the scheme was beneficial but that the SNA system has to deal with a very diverse range of needs, age groups, developmental stages and school settings, and it was suggested that a 'broader range of support options [is] required to address students' additional care needs'.[216] Acting on these findings, the Government approved a new School Inclusion Model trialling for the 2019/2020 school year whereby the model was implemented in 75 schools in one HSE Community Health Organisation area.[217] The model's principal features include a new frontloaded allocation of SNAs in line with profiled needs of participating schools, additional provision for these schools under the National Educational Psychological Service (NEPS), and the establishment on a pilot basis of a NCSE Regional Support Team, which includes specialists in relevant disciplines. In addition, the initiative includes the development of a national training programme for

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[211] Department of Education and Skills, *Review of the Pilot of a New Model for Allocating Teaching Resources to Mainstream School to Support Pupils with Special Educational Needs* (Dublin, 2016); Department of Education and Skills, 'Circular to the management authorities of all mainstream primary schools: special education Teaching Allocation', Circular No 0013/2017.

[212] Carl O'Brien, 'Changes in appeals process for learning supports at schools' *The Irish Times* (Dublin, 27 March 2017).

[213] Children's Rights Alliance 'Report Card 2020' (Dublin, 2020) 30.

[214] Equal Status Act 2000, s4 and 7,

[215] National Council for Special Education 'Special Needs Assistant (SNA) Scheme: Information for Parents/Guardians of Children and Young People with Special Educational Needs' (Dublin, 2015).

[216] National Council for Special Education, '*Comprehensive Review of the Special Needs Assistant Scheme: A New School Inclusion Model to Deliver the Right Supports at the Right Time to Students with Additional Care Needs*' (Dublin, 2018).

[217] Children's Rights Alliance 'Report Card 2020' (Dublin, 2020) 30.

SNAs and a pilot roll-out of this, and the provision of a nursing service for children with complex medical needs.[218]

Third level and further education

The National Plan for Equity of Access to Higher Education was published in December 2015. The plan's vision was to ensure that the student body entering, participating in and completing higher education at all levels reflects the diversity and social mix of Ireland's population. The plan set out five goals and more than thirty actions, developed following widespread consultation with stakeholders, with the aim of supporting increased access and participation in higher education by six main target groups, i.e. entrants from disadvantaged socio-economic groups that have low participation in higher education; first-time mature students; students with disabilities; part-time/flexible learners; further education and training award holders; and Irish Travellers.[219]

A Progress Review of the National Access Plan was published in 2018 to report on progress to date in the meeting of targets and objectives set under the National Plan for Equity of Access to Higher Education 2015–2019. The Review highlighted important achievements including increases in participation rates across a number of the target groups, with particularly high increases for students with disabilities and among socio-economically disadvantaged groups.[220]

College choices for would-be students with disabilities today are much wider, as more institutions acknowledge they deserve the same opportunities as their peers. Universities and colleges have been developing disability support services to cater for a wide range of special needs, and there are also schemes to make it easier for disabled students to get to third-level in the first place. One obvious measure of that progress has been the rise in participation rates. According to the Association for Higher Education Access and Disability (AHEAD), students with disabilities make up more than 5 per cent of the total student population in Ireland across 27 institutions, which differs significantly from 20 years ago, when the figure was less than 1 per cent. [221] However, the AHEAD, which surveys participation rates annually, says that while the overall picture is positive, there are a 'number of persistent trends and barriers which raise questions for the education sector'.[222]

According to Cradden, 'the main concerns are that students with disabilities are more likely to study humanities and arts subjects than other students, that they are very under-represented on part-time courses, and that they are not progressing onto

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[218] Department of Education and Skills, 'Press Release: Minister McHugh announces trial of a new School Inclusion Model to provide the right supports at the right time to students with additional needs' (27 March 2019) <https://www.education.ie/en/Press-Events/Press-Releases/2019-press-releases/PR19-03-27-1.html> accessed 17 April 2020.

[219] Higher Education Authority, 'National Plan for Equity of Access to Higher Education 2015-2019'. (Dublin, 2015).

[220] Higher Education Authority, 'HEA welcomes publication of Progress Review of the National Plan for Equity of Access to Higher Education' (21 December 2018) <https://hea.ie/2018/12/21/hea-welcomes-publication-of-progress-review-of-the-national-plan-for-equity-of-access-to-higher-education/> accessed 18 April 2020.

[221] John Cradden 'Overcoming disability as a barrier to college education' *The Irish Times* (Dublin, 11 January 2017).

[222] ibid; See also AHEAD, 'AHEAD Launch Report on Numbers of Students with Disabilities in Higher Education' <https://www.ahead.ie/part-rates-launch-2017-18> accessed 25 July 2020.

postgraduate study at the same rate as non-disabled graduates'.[223] AHEAD believes there are 'some issues with the career guidance that students with disabilities receive, particularly with what looks like a failure to inform and encourage them to look at industries and occupational areas where the employment opportunities may be greater, such as STEM, ICT, financial services, manufacturing and leisure industries'.[224]

While there are funding schemes that are open to all students at third level, a number of sources of funding specifically for students with disabilities exist. Further, there are a number of scholarships aimed at students with disabilities. The main funding scheme is the Fund for Students with Disabilities, which provides funding under three categories: assistive technology equipment and software, personal and academic support (sign language interpreter, note-taker, personal assistant), and transport (taxis or mileage allowance). The funding is allocated to the college rather than the student and is not means-tested. However, only full-time students are eligible; those on part-time courses cannot apply. Furthermore, this funding in most third level institutions is only available to EU students and an equivalent is not provided to non-EU international students.

Of all the supports available to prospective students with disabilities, the Disability Access Route to Education (DARE) scheme probably ranks as one of the most significant. DARE offers reduced points places to school-leavers whose disabilities are judged to have had a 'negative impact' on their second-level education. While most colleges participate in the DARE scheme, not all do. However, colleges outside of these schemes still offer a wide range of supports, including disability support services. Whether gaining entry through DARE or not, students with disabilities are still entitled to avail of disability-related supports once a disability has been verified. The criteria for participation in the DARE scheme used to be exclusively medical, but has since broadened to include educational impact, which involves both an applicant and a school statement.[225]

In Ireland, much of the policy focus has been on inclusive education and removal of barriers for people with disabilities entering higher education and remaining in university. This is evident in the number of students with disabilities in further and higher education which has led to a substantial increase in numbers seeking disability services, disability funding and reasonable accommodations.[226]

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[223] John Cradden 'Overcoming disability as a barrier to college education' *The Irish Times* (Dublin, 11 January 2017).

[224] ibid.

[225] ibid.

[226] Higher Education Authority, 'Review of the Fund for Students with Disabilities' (Dublin 2017).

6.1.2 Key barriers to the realisation of rights

Lack of enforceable rights and comprehensive strategy for inclusion in education system as a whole

As noted above, the failure to commence the main provisions of the EPSEN Act 2004 means that children do not have legally enforceable rights to specific supports in their education. It is therefore essential that there is a legislative base to ensure that students with special educational needs and children with disabilities can get access to assessments and be provided with the necessary resources to allow them to engage with school and improve their experience of education as a whole.

In 2016, the UNCRC expressed concern about Ireland's lack of a 'comprehensive strategy for the inclusion of children with disabilities in mainstream education and the encouragement of their autonomy',[227] recommending that the State should 'adopt a human rights-based approach to disability'.[228] Further, actions were recommended to 'train and employ a sufficient number of specialized teachers and professionals in order to provide special needs education support' and to establish 'a clear and objective framework to ensure that children with disabilities are provided with reasonable accommodation for their education needs'.[229] Under the UNCRPD, children with special educational needs have a right to individualised support and reasonable accommodations to enable their effective participation in the general education system.[230] In 2016, the UNCRPD emphasised the central importance of inclusion in the education system, stating that this 'involves a process of systemic reform … to provide all students … with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences'.[231]

Lack of a clear image of Inclusive education

The main supports provided to students with special educational needs include special needs assistants (in mainstream or special schools), additional teaching hours outside the mainstream classroom, and special classes or units attached to mainstream schools. While the fact that most children with disabilities are being educated in mainstream environments is to be welcomed, the reality is that many students are not receiving the supports they need in environments which are not adapted for their needs. This has been recognised by the UNCRPD in its General Comment on Inclusive Education, which noted that 'Placing students with disabilities within mainstream classes without accompanying structural changes … does not constitute inclusion'.[232]

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[227] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4), para 47(a).

[228] ibid, para 48.

[229] ibid.

[230] UNCRPD, art 24.

[231] UN Committee on the Rights of Persons with Disabilities, General comment No. 4 (2016) Article 24: Right to inclusive education (CRPD/C/GC/4) para 11.

[232] ibid.

Organisations such as Inclusion Ireland have raised concerns that inadequate levels of supports have resulted in children being placed on reduced timetables in school.[233] Among the issues identified were the non-recording and lack of monitoring of reduced timetables, the lack of supports and expertise within schools, and the lack of accessible information for parents on their rights and their exclusion from decisions affecting their children. In September 2019, the Department of Education and Skills announced draft guidelines on the use of reduced timetables as well as procedures to be followed by schools considering and using this option. Intentions related to the requirement of schools to give formal notification of reduced timetable use to Tusla Education Support Service which would be tasked with usage monitoring. The guidelines were aimed 'to ensure that the use of reduced timetables is limited solely to those circumstances where it is absolutely necessary' such as in instances where they support a child to remain in school and build towards a full day.[234]

The latest report by Inclusion Ireland provides that large class sizes are a significant obstacle to effective teaching and learning and make it difficult for pupils with special educational needs both educationally and socially. The ratio must be reduced to ensure equality and a quality education system that serves all children.[235]

Special education, including special classes have been a part of the Irish education system since the 1970's. The UNCRPD Committee define segregated education as

> "*Segregation* occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities."[236]

Based on this definition special classes are in fact segregated education. The CRC Committee is supportive of inclusive education but does note that the extent of inclusion may vary and that a continuum of services must be available "where fully inclusive education is not feasible to achieve in the immediate future."[237] Accordingly the CCRC appears to accept that while access to an effective education is an immediate duty, in contrast inclusive education is a goal, one that must be progressively achieved. However, the significant increase in the number of special classes suggests that the move is not towards inclusion but towards segregation within a mainstream setting. A 2016 study highlighted inconsistencies in how teachers are appointed to these classes, low levels of integration throughout the school (with some notable exceptions), a mixed experience by students in special classes.[238]

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[233] Inclusion Ireland and Technological University of Dublin, 'Education, Behaviour and Exclusion: The Experience and Impact of Short School Days on Children with Disabilities and their Families in the Republic of Ireland' (Dublin, 2019).

[234] Department of Education and Skills, 'Press Release: Minister for Education and Skills invites education partners to give views on proposed guidelines on reduced timetables' (23 September 2019) <https://www.gov.ie/en/press-release/b0615f-minister-for-education-and-skills-invites-education-partners-to-give/> accessed 19 April 2020.

[235] Inclusion Ireland, 'Pre-Budget submission 2020 - Inclusion Ireland' <http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1651/budget-2020-full-submission-final.pdf> accessed 10 April 2020.

[236] UN Committee on the Rights of Persons with Disabilities, General comment No. 4 (2016) Article 24: Right to inclusive education (CRPD/C/GC/4)

[237] UN Committee on the Rights of the Child, General Comment No. 9 (2006): The Rights of Children with Disabilities (CRC/C/GC/9) para 66.

[238] Joanne Banks et al. 'Special Classes in Irish Schools: Phase 2: A Qualitative Study' (Dublin: National Council for Special Education, 2016).

Low expectations for children with disabilities in education

In 2018 a report on disability and discrimination in Ireland provided that parents and teachers of children with disabilities have lower expectations compared to children without disabilities. This has clear long-term implications for accessing further and higher education and entry into the labour market for people with disabilities. For those that do progress to further or higher education, issues exist around transition planning and retention. Further, discrimination on entry to higher education can vary by disability type.[239]

In a 2017 report, Mooney and O'Rourke found that some of the most significant motivational/dispositional barriers included age, mental health, learning difficulties, confidence, stigma, self-esteem, a lack of fundamental skills (Information and Communication Technology (ICT), literacy, numeracy), and a negative experience of education resulting in a lack of value placed on education.[240] These resulted in a lack of trust in the quality of Further Education and Training (FET), confusion about different levels of commitment, time and requirements to obtain qualification at the same level and reduces the ability for progression from FET into meaningful and long-term career.[241]

6.1.3 Measures to overcome identified barriers

Legislative measures

It is necessary to provide a legislative base for the educational rights of children with disabilities. Ideally, legislation giving effect to the provisions of Article 24 UNCRPD would be introduced. Any such legislation should clearly indicate what the goal of educational interventions for children with disabilities. A second option would be to enact EPSEN 2004, however, it would need to be considerably amended in order to ensure that it was compliant with the UNCRPD.

Administrative and other measures

Capacity building around inclusive leadership is vital and is necessary to drive culture change. Teacher training is segregated as teachers either undertake general education or special education. The special education funding model is reported separately from the general education spending. There is a significant increase in special classes/autism units. All of these actions militate against inclusion – therefore it is necessary to introduce capacity building about inclusion throughout the education system. This could include the preparation of comprehensive guidance on the best practice in relation to special classes and autism units and how these classes should provide a pathway to mainstream education. The goal is to realise the right to inclusive education, the proliferation of such units without clear pathways into the mainstream setting is of concern. If necessary, schools should have targets to ensure that there is movement out of special/segregated settings.

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[239] Joanne Banks, Raffaele Grotti, Éamonn Fahey and Dorothy Watson, 'Disability and Discrimination in Ireland: evidence from the QNHS equality modules 2004, 2010, 2014' (Dublin: Economic and Social Research Institute, 2018) 12.

[240] Robert Mooney and Claire O'Rourke, 'Barriers to further education and training with particular reference to long term unemployed persons and other vulnerable individuals' (Dublin: Solas and. Ámarach Research, 2017).

[241] ibid.

In line with the UNCRPD teachers and education staff need to be supported to enable them to develop an inclusive culture within schools. This would involve developing core values and competencies to accommodate inclusive learning. In particular, it would be necessary to undertake an assessment of teacher training, with a view to exploring the potential of amalgamating special education teacher training and general teacher training. Currently teachers in the general education system do not have sufficient training to teach a fully diverse class, and they need to be supported to do so.

Currently, special education funding is reported separately from general education. It is sometimes described in terms of 'spiralling costs.'[242] Funding criteria have changed recently to a block grant to schools and schools have greater autonomy on how the money is spent but without adequate capacity building and support around inclusive leadership. Additionally, there is no independent appeals process in respect of funding decisions.

Separately, supports currently provided are not adequately resourced. Significant additional resources are necessary to ensure that children with disabilities access adequate supports in a timely fashion.[243]

6.2 Play

Argued as underpinning the well-being, health, and development of children, play as a concept has a special place in children's lives. Despite there being different definitions of play and no international consensus on naming different play forms, the evidence of its importance is consistently documented.[244]

Children's access to play and recreational activities is recognised internationally as a fundamental human right. The UNCRC recognises the right of the child 'to engage in play and recreational activities appropriate to the age of the child' including participation in cultural life.[245] Article 30 of the UNCRPD guarantees persons with disabilities the right to participate in cultural life, recreation, leisure and sport on an equal basis with others. This is seen as including play for children with disabilities, and places a clear obligation on all States Parties to ensure that children with disabilities have equal access to play, recreation and leisure and sporting activities, including those activities in the school system.[246]

General Comment No. 17 (GC17) of the UNCRC Committee, is viewed as one of the most significant documents regarding the right to play for children.[247] The UNCRC Committee drafted GC17 as a result of State Parties' poor recognition of the right to play, resulting

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[242] Carl O'Brien, 'Why is the cost of special education soaring? *The Irish Times* (Dublin, 22 July 2017).

[243] Ombudsman for Children's Office, *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (Dublin, 2020) 7 and 27.

[244] Stuart Lester and Wendy Russell 'Children's Right to Play: An Examination of the Importance of Play in the Lives of Children Worldwide' (2010) Working Papers in Early Childhood Development, No. 57. Bernard van Leer Foundation.

[245] UNCRC, art 31(1).

[246] UNCRPD, art 30(5)(d).

[247] UN Committee on the Rights of the Child, General comment No. 17 on the right of the child to rest, leisure, play, recreational activities, cultural life and the arts (art. 31) 2013 (CRC/C/GC/17).

in poor investment, and limited progress in legislation and policy.[248] Specifically, the GC17 identified children with disabilities among those at risk of play deprivation.[249] They also noted that when investment was made into play provision, it over-emphasised structured and organised activities, for example, compulsory sports, rehabilitative activities for children with disabilities, rather than recognising the need to provide time and space for children.[250]

For children with disabilities the GC17 identified many barriers to play, including physical barriers, inaccessible play spaces and transport, policies that exclude participation on the grounds of safety, communication barriers, poor investment in technologies, and lack of involvement of children in designing for play.[251] It places an obligation on States Parties to make 'accessible and inclusive environments and facilities' available to children with disabilities to allow them to play and to raise awareness among adults and other children through age appropriate supports and assistance.[252]

The Committee notes that the urge to play is a spontaneous reaction of children who will search for opportunities to do so, including in environments found 'most unfavourable'; it therefore urges States to create certain conditions which will enable children to realise their article 31 rights to the maximum extent.[253] Such conditions include space and opportunities to play outdoors unaccompanied in a diverse and challenging physical environment in addition to opportunities to experience, interact with and play in natural environments and the animal world.[254]

6.2.1 Current Irish Context: Overview of law and policy

There are several commitments at a public policy level in Ireland in relation to children's right to play. Ready, Steady, Play! A National Play Policy illustrated the Government's recognition of the importance of play, and a commitment to making sure that equitable and inclusive play is facilitated for all children, particularly children who are marginalised, disadvantaged or who have a disability.[255] Subsequently, the sectoral plan prepared by the Department of the Environment, Heritage and Local Government committed to ensuring public amenities, such as playgrounds, will be 'accessibility-proofed at design and construction/development stage'.[256]

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[248] Helen Lynch and Alice Moore. 'What barriers to play do children with disabilities face?' in Pedro Encarnação, Sylvie Ray-Kaeser and Nicole Bianquin (eds) *Guidelines for supporting children with disabilities' play* (Sciendo 2018).

[249] UN Committee on the Rights of the Child, General comment No. 17 on the right of the child to rest, leisure, play, recreational activities, cultural life and the arts (art. 31) 2013 (CRC/C/GC/17), para 3.

[250] ibid, para 42.

[251] Helen Lynch and Alice Moore, 'What barriers to play do children with disabilities face?' in Pedro Encarnação, Sylvie Ray-Kaeser and Nicole Bianquin (eds) *Guidelines for supporting children with disabilities' play* (Sciendo 2018).

[252] UN Committee on the Rights of the Child, General comment No. 17 on the right of the child to rest, leisure, play, recreational activities, cultural life and the arts (art. 31) 2013 (CRC/C/GC/17), para 24.

[253] ibid. See also Kilkelly, Ursula, Helen Lynch, Alice Moore, Angela O'Connell, and Sarah C. Field 'Children and the outdoors: Contact with the outdoors and natural heritage among children aged 5 to 12: current trends, benefits, barriers and research requirements' (Heritage Council, 2016) 12.

[254] UN Committee on the Rights of the Child, General comment No. 17 on the right of the child to rest, leisure, play, recreational activities, cultural life and the arts (art. 31) 2013 (CRC/C/GC/17).

[255] National Children's Office, *READY, STEADY, PLAY! A National Play Policy* (2004)<https://assets.gov.ie/24440/03bb09b94dec4bf4b6b43d617ff8cb58.pdf> accessed 1 May 2020.

[256] Department of Environment, Heritage and Local Government, *Sectoral Plan under the Disability Act 2005* (Government of Ireland, December 2006) <https://www.housing.gov.ie/sites/default/files/migrated-files/en/Publications/LocalGovernment/Administration/FileDownLoad,2011,en.pdf> accessed 1 May 2020.

While there were 168 playgrounds in the country in 2004 under the management of Local Authorities, 2012 saw an estimated 900 playgrounds in the country, with most of these being managed by Local Authorities.[257] The Minister established the first ever National Local Authority Play and Recreation network (LAPRN) in February 2012, bringing together for the first time key personnel responsible for implementation of play and recreation policy in local communities across the country.[258] Since 2013, a capital grant funding scheme has provided €250,000 annually for play and recreation.[259] In 2020, €450,811 was awarded to 27 local authorities under a capital grant funding scheme, including for accessibility upgrades. [260] In order to qualify for funding applicants must demonstrate how the improvements planned will increase access to the facility for children or young people with disabilities.[261]

There is no national list for accessible outdoor amenities. Each local authority is responsible for ensuring the accessibility of the playgrounds and facilities it manages.[262] Semi State bodies and voluntary organisations have collaborated to develop a guide to creating accessible outdoor amenities.[263]

Outcome One of the BOBF policy aims to ensure children enjoy play, recreation, sports, arts, culture and nature.[264] As a result, a commitment was made to enable greater access to sports, arts and culture for all children and young people, including through facilitating collaboration between sports, youth, arts and cultural organisations and schools and preschools to enrich the educational experience of all. Additionally, the government stated its commitment to continue the development of play and recreation spaces for both children and young people, from playgrounds (for multiple age ranges) to youth cafés, sports and leisure centres, and where possible look to weatherproof these spaces.[265] An indicator set for the implementation of this policy was published in 2017.[266] The indicators in relation to play and recreation include information on engagement with hobbies, participation in sport and other leisure activities, play with family and screen time.[267] However, neither the indicators nor the baseline data is disaggregated on the basis of disability and therefore, it is not possible to monitor the impact of the measures in place on children with disabilities.

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[257] Dáil Debate, 25 October 2012, vol 780, no 3.

[258] ibid.

[259] Dáil Debate, 20 May 2020 vol 993 no 3.

[260] Department of Children and Youth Affairs, 'Minister Zappone announces funding to Local Authorities for the refurbishment of playgrounds' (8 May 2020) <https://www.gov.ie/en/press-release/c896d5-minister-zappone-announces-funding-to-local-authorities-for-the-refu/> accessed 08 June 2020.

[261] Email communication from Department of Children and Youth Affairs to report authors 3 September 2020.

[262] See for example Wexford County Council 'Draft Playground Strategy 2017 – 2020' (February 2017) <https://www.wexfordcoco.ie/sites/default/files/content/Community/Playground%20Strategy%202017-2022%20-%20adopted%2008.05.2017.pdf> accessed 8 June 2020; Galway City Council 'Playground Information' <https://www.galwaycity.ie/playgrounds-information> accessed 8 June 2020.

[263] Irish Wheelchair Association and Sport Ireland 'Great Outdoors: A Guide for Accessibility' (October 2018) <https://www.sportireland.ie/sites/default/files/2019-10/great-outdoors-a-guide-for-accessibility.pdf> accessed 8 June 2020.

[264] Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The National Policy Framework for Children And Young People, 2014-2020* (Dublin 2014) 49.

[265] ibid 58.

[266] Department of Children and Youth Affairs, *An Indicator Set for Better Outcomes Brighter Futures-the National Policy Framework for Children and Young people 2014-2020* (Dublin, 2017) <https://www.gov.ie/pdf/?file=https://assets.gov.ie/27126/9b1f25ec7da348e6921373e7e91e1ae3.pdf#page=1> accessed 28 May 2020.

[267] ibid 22.

Let's Play Ireland is the latest government-led initiative aimed at promoting play for all children living in Ireland during the COVID-19 emergency.[268] There were only two links provided to resources to support play for children with disabilities.[269]

6.2.2 Key barriers to the realisation of rights

Lack of national guidance and oversight

Despite capital funding from the DCYA and national policies developed in this regard, local authorities retain responsibility for the playgrounds and amenities in their area. This has resulted in a lack of national oversight and guidance which has been highlighted by a number of organisations and reports.[270] Additionally, despite the National Play Policy identifying the need for a universal design approach to play spaces, there are no national policies or 'good practice' guidelines developed to guide this process.[271]

Insufficient number of accessible play facilities

Research completed for the Centre for Excellence in Universal Design found that many playgrounds were 'unsuitable spaces' due to a range of factors, including age and disability or accessibility requirements.[272] Children and adults surveyed identified physical design features, such as layout and lack of accessible play equipment, among the key barriers.[273]

Lack of information and data

Lynch argues that in order to employ a rights-based approach to play, policy developments must be evidence-informed and research must focus on the experiences and play preferences and needs of children with disabilities in Ireland.[274] There is limited data available in this area in Ireland despite the Irish National Play Policy highlighting this as a key issue.[275]

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268 Department of Children and Youth Affairs, *Let's Play Ireland* (22 April 2020) <https://www.gov.ie/en/campaigns/lets-play-ireland/> accessed 28 May 2020.

269 Department of Children and Youth Affairs, *Let's Play Outdoors* (19 May 2020) <https://www.gov.ie/en/publication/49d91a-lets-play-outdoors/> accessed08 June 2020.

270 See for example Children's Rights Alliance, 'Are we there yet? Parallel Report to Ireland's Third and Fourth Combined Report under the UN Convention on the Rights of the Child' (Dublin, 2015); Ursula Kilkelly, Helen Lynch and Alice Moore 'Children and the outdoors: Contact with the outdoors and natural heritage among children aged 5 to 12: current trends, benefits, barriers and research requirements' (Heritage Council, 2016) 33.

271 Children's Rights Alliance, 'Are we there yet? Parallel Report to Ireland's Third and Fourth Combined Report under the UN Convention on the Rights of the Child' (Dublin, 2015) 93.

272 Helen Lynch, Alice Moore, Claire Edwards and Linda Horgan 'Community Parks and Playgrounds: Intergenerational Participation through Universal Design: Final Report' (December 2018) 82 <http://nda.ie/Publications/Others/Research-Promotion-Scheme/Community-Parks-and-Playgrounds-Intergenerational-Participation-through-Universal-Design1.pdf> accessed 8 June 2020.

273 ibid.

274 Helen Lynch 'Playspaces: Children with disabilities and social inclusion- Resilience and social support' (June 2017) Children's Research Digest 4(1) Special conference issue <https://childrensresearchnetwork.org/knowledge/resources/playspaces> accessed 20 April 2020.

275 ibid.

6.2.3 Measures to overcome identified barriers

Legislative measures

Legislative reform in this area is required which clearly states that all playgrounds and facilities, and in particular those funded under the DCYA's capital grant scheme or owned by local authorities, must be accessible to children with disabilities. This reform could be an amendment to the Disability Act 2005 or the introduction of new legislation in relation to accessibility.

Administrative and other measures

Comprehensive guidance documents should be produced to aid local authorities and community groups when building or renovating playgrounds.[276] Children with disabilities should be involved in the development of such guidance, in line with the UNCRPD[277] and UNCRC best practice[278], to ensure the guidance adequately represents the barriers they frequently encounter and the most appropriate solutions.

Public play facilities, in particular those in receipt of DCYA funding, should also be subject to regular maintenance and inspection to ensure compliance with the guidelines. Overall, an assessment process should be put in place to assess the level of accessible play and recreational facilities available and their suitability for children and young people with a variety of disability or impairment types.[279] Access officers within the DCYA or local authorities should be given a role within the inspection process to ensure accessibility based on the guidelines and drawing on the views and experiences of a consultative panel.

Data collection and dissemination

Data should be collected from children with disabilities and their representatives regarding the barriers they encounter in accessing play facilities and their preferences regarding play equipment and facilities. This should inform any guidance drafted, as set out above, and future policies in relation to funding or national schemes to support play and recreation.

In the interim, and in the absence of universally accessible playgrounds and recreational facilities, a list of facilities with accessible equipment should be made publicly available via local authority websites or the DCYA's website to facilitate access for children with disabilities.

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276 Helen Lynch, Alice Moore, Claire Edwards and Linda Horgan 'Community Parks and Playgrounds: Intergenerational Participation through Universal Design: Final Report' (Dublin: National Disability Authority, 2018) 82 <http://nda.ie/Publications/Others/Research-Promotion-Scheme/Community-Parks-and-Playgrounds-Intergenerational-Participation-through-Universal-Design1.pdf> accessed 8 June 2020.

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

278 See for example, UN Committee on the Rights of the Child, Concluding Observations on the Fifth Report of the United Kingdom of Great Britain and Northern Ireland 2016 (CRC/C/GBR/CO/5) .

279 Helen Lynch, Alice Moore, Claire Edwards and Linda Horgan 'Community Parks and Playgrounds: Intergenerational Participation through Universal Design: Final Report' (Dublin: National Disability Authority, 2018) 82 <http://nda.ie/Publications/Others/Research-Promotion-Scheme/Community-Parks-and-Playgrounds-Intergenerational-Participation-through-Universal-Design1.pdf> accessed 8 June 2020.

7. Cluster 2 – Inclusion and Belonging

7.1 Family and alternative care

The right to family life is recognised in many of the international human rights instruments, including the UNCRC and UNCRPD. The importance of the family in the lives of children underpins many of the provisions in the UNCRC.[280] Article 23 of UNCRPD is particularly relevant as it protects the right of children with disabilities to a family life and obligates the State to provide the supports and services necessary to realise this right. Article 23(4) obligates State Parties to ensure that a child with disabilities is not separated from his or her parents against their will or when there are no reasonable grounds in law. When an immediate family member is unable to care for a child with disabilities every effort must be made to find alternative care in the wider family or in a family or community setting.[281] Article 19 of the UNCRPD also protects the inclusion of persons with disabilities in the community. It requires governments to provide the range of required supports to prevent isolation or segregation from the community.

There is a broad consensus that children's interests are generally best protected in the family environment.[282] The importance of parents and family to a child's development and well-being has been widely accepted,[283] with the view also shared by children. Children have voiced the importance of having a family and relationships with significant others as fundamental to their perceived well-being.[284] When a child's own family is unable to adequately care for the child, even with the provision of support, the evidence consistently demonstrates that alternative family and community-based forms of care are more likely to meet the needs of children than residential care institutions.[285]

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[280] For example, Article 7 protects the right of the child to know and be reared by his or her parents, Article 9 enshrines the right of a child who is separated from one or both parents to maintain regular and direct contact and Article 18 acknowledges that parents have the primary responsibility for the upbringing and development of the child.

[281] UNCRPD, art 23(5).

[282] Danielle Kennan and Celia Keenaghan 'Children's Rights and the Family: A Commentary on the Proposed Constitutional Referendum on Children's Rights in Ireland' (National University of Ireland Galway and University of Ulster, 2012) 7.

[283] Eileen Munro 'The Munro Review of Child Protection Interim Report: The Child's Journey' (London: Office of the Children's Commissioner, 2011).

[284] Collette McAuley, Roger Morgan and Wendy Rose, 'Children's views on child well-being' in Colette McAuley, Wendy Rose and Gillian Pugh (eds), *Child Well-Being: Understanding Children's Lives.* (Jessica Kingsley 2010). Child well-being: Understanding children's lives (2010) 39-66.

[285] Council of Europe, 'Alternative Care' (Strasbourg, 2020) <https://www.coe.int/en/web/children/alternative-care> accessed 26 April 2020.

7.1.1 Current Irish Context

7.1.1.1 Profile of children with disabilities

Tusla and HIQA publish official statistics on the number of children in the care of the State, disaggregating the data to account for the number of children in public and private foster care, residential care and special care. At the time of writing, the most recent data recorded 5,957 children in the care of the State.[286] This data is not disaggregated to account for the number of children with disabilities or other minorities such as ethnic groups in care. However, elsewhere it is reported that the number of children in foster care with a moderate or profound disability in September 2018 was 477.[287]

The Child Care Law Reporting Project has consistently found that there is a high proportion of children going into care with special needs. Accounting for children in all care placements and all forms of disability, their figures are significantly higher. The figures reported, in 2015, show that one in four children taken into care have special needs, ranging from psychological, physical and education special needs, with some having more than one type of special need.[288] HIQA recently published figures on the number of places for children with disabilities in designated residential centres for people with disabilities. It reported that in October 2018, there were 8,287 places for adults, 320 for children and a further 287 placements for either adults or children with disabilities.[289]

7.1.1.2 Overview of law and policy

Article 41 of the Irish Constitution protects the rights of the family and includes a number of provisions imposing duties on the State. Article 41.1 recognises the family as the ‘natural, primary and fundamental unit group of society’. Despite the prominence given in the Irish Constitution to protecting the family unit, the new article 42A.4 requires provision to be made by law for the best interests of the child to be ‘the paramount consideration’ in child protection and care, adoption and family law proceedings. The Child Care Act, 1991 is the primary piece of legislation governing the protection and welfare of children in Ireland. Under the Child and Family Agency Act 2013, it is Tusla’s statutory duty to promote their welfare and protection in accordance with the Child Care Act. When children require admission to care, they are accommodated through placement with relatives, placement in foster care or residential care. The Child Care Act, 1991 makes provision for detailed regulations governing these forms of care placements. These regulations require a comprehensive plan to be developed to meet the needs of the child being taken into care.

All placements are also required to adhere to the HIQA National Standards, governing foster care and residential care. The National Standards for Children’s Residential Centres were published by HIQA in 2018, superseding its 2001 document, to ensure that

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[286] Tusla, *Monthly Performance and Activity Report*, (June 2020).,

[287] Ombudsman for Children’s Office, *Molly Two Years On: Have Tusla and the HSE delivered on commitments to children with a disability in the care of the State?* (Dublin, 2020).

[288] Carol Coutler, ‘Final Report Child Care Law Reporting Project’ (Dublin: Child Care Law Reporting Project, 2015).

[289] Health Information and Quality Authority, *Five years of regulation in designated centres for people with a disability* (Dublin, 2019) 17.

children living in children's residential centres are provided with child-centred, safe and effective care and support.[290] They define child-centred services as services which 'value diversity and are inclusive of all groups of children who may be in a minority as a result of their culture, religion, race, ethnicity, sexual orientation, gender identity or disability'.[291]

Under the Health Acts, children with disabilities can be placed in designated residential centres for children with disabilities, provided by the HSE or voluntary disability service providers, with the consent of their parents. These arrangements are not subject to the same oversight as alternative care provided under the Child Care Act 1991 and they are not subject to the HIQA National Standards on Residential Care. In 2013, HIQA published National Standards for designated residential centre for children with disabilities.[292] The Standards specific to children with disabilities are clustered around eight themes, which are broadly focused on the provision of individualised support and care, delivering effective and safe services and nurturing their health and development.

At the policy level, in 2011 Government published its policy 'Time to Move on from Congregated Settings – A Strategy for Community Inclusion'.[293] The Strategy proposes a new model of support within the community, moving people with disabilities from congregated settings to the community. In relation to children, the Strategy recommends that, 'purpose built community housing funded by the HSE should be provided for any children under 18 years old moving from congregated settings'.[294] The 2016 Programme for Partnership Government contained a commitment to reduce the number of people with disabilities, including children, in congregated settings from 4,000 (as of 2008) to one third by 2021.[295] The 2020 Programme for Government renewed its commitment to this Strategy.[296]

BOBF recognises the family as the fundamental group of society and the natural environment for the growth and wellbeing of children, while also acknowledging the complexity of contemporary family structures. Under the fifth national outcome, 'connected, respected and contributing', the Government aspires to all children and young people being part of positive networks of friends, family and community. Supporting parents is one of the policy framework's six transformational goals. It states that ensuring all parents are appropriately supported and that there are adequate resources to effectively parent is fundamental to the realisation of children's rights.[297] The policy also recognises that the State, 'as corporate parent to children in care, has a responsibility to ensure that supports are prioritised to facilitate these children and young people to reach their full potential across the five national outcomes'.[298]

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[290] Health Information and Quality Authority, *National Standards for Children's Residential Centres* (Dublin, 2018).

[291] ibid 20.

[292] Health and Information Quality Authority, *National Standards for Residential Services for Children and Adults with Disabilities* (Dublin, 2013).

[293] Health Service Executive, *Time to Move on from Congregated Settings-A Strategy for Community Inclusion* (Dublin, 2011).,

[294] ibid, 17.

[295] Government of Ireland, Programme for Partnership Government (Dublin, 2016).,

[296] Government of Ireland, Programme for Government, 'Our Shared Future' (Dublin, 2020).

[297] Department of Children and Youth Affairs, *Better Outcomes Brighter Futures: The National Policy Framework for Children and Young People 2014-2020* (Dublin, 2014) 26.

[298] ibid, 28.

Central to the BOBF outcome 'economic security and opportunity' is the government's commitment to effective transitions. This commitment provides that 'all young people leaving care, detention or residential disability settings are adequately prepared and supported to negotiate the system and transition to stable independent living, further education, training or employment through the development and implementation of a quality aftercare plan and the development of protocols in relation to accessing housing, education and training'.[299]

7.1.2 Key barriers to the realisation of rights

Inadequate Supports for Parents

Inadequate supports for parents can result in poorer outcomes and thereby present barriers to the realisation of the rights of children with disabilities. According to a Growing Up in Ireland (GUI) study, maternal well-being in Ireland was found to be a significant predictor of families' outcomes as, difficulties 'in the home environment and parenting – specifically maternal negativity, depression, parenting stress and the use of physical punishment – were particularly important predictors of children's adjustment'.[300] Similarly, Rodriguez et al. found that maternal well-being is the largest predictor of overall family outcomes and that improving maternal well-being contributed to improved family outcomes.[301] This research underscores the importance of the State providing the wide range of supports that the parents of children with disabilities require.

The Government is committed to providing a range of supports under the Disability Act 2005 and its provision for an assessment of need for people with disabilities, the National Carers' Strategy[302], the First 5 Government Strategy[303], particularly in the context of supporting babies and young children with disabilities and their families, and through the range of income supports provided for families caring for a child with disabilities.[304] However, research indicates that there are inadequacies in the provision of parental supports to parents of children with disabilities in Ireland. A 2016 report on family carers' experiences of caring for a person with an intellectual disability, documented that parents and carers of children with intellectual and developmental disabilities experience higher levels of stress in parenting and increased risk of poor physical health.[305] Mothers of children with an intellectual disability are much more likely to experience higher levels of anxiety and depression and families of children with an intellectual disability may also experience other problems such as increased financial strain. Once again, this research highlighted that prolonged carer stress can have other

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[299] ibid, 94.

[300] Elizabeth Nixon, 'Growing Up in Ireland: How Families Matter for Social and Emotional Outcomes of 9 Year Old Children' (Dublin: Department of Children and Youth Affairs, 2012).

[301] Leonore Rodriguez, Anne Cassidy and Carmel Devaney, 'Meitheal and Child and Family Support Networks Final Report: Tusla's Programme for Prevention, Partnership and Family Support' (UNESCO Child and Family Research Centre, 2018) 14.

[302] Department of Health, *The National Carers' Strategy – Recognised, Supported, Empowered* (Brunswick Press Ltd).

[303] Government of Ireland, *First 5 – A Government Strategy for Babies, Young Children and their Families 2019-2028* (Dublin, 2019).

[304] For example, the Carers Benefit, the Carers Allowance and the Domiciliary Carers Allowance.

[305] Attracta Lafferty et al. 'Family carers' experiences of caring for a person with intellectual disability' (Dublin: University College Dublin, 2016) 29-32.

significant consequences for a family's resilience and for the child with an intellectual disability, leading to an increased risk of marital problems and family dysfunction. The study found that while most family carers were in receipt of a range of services, some have not received the services they require.

A critical service for family carers is respite services. The 2016 report on family carers found that just over half of the respondents who required crisis respite care did not receive this service.[306] The HSE National Service Plan 2019 provides a Government commitment to invest €10 million in respite services for children and adults with disabilities.[307] However, the Government has acknowledged that there remains inadequate respite care provision for parents, particularly in certain geographical areas.[308] Research conducted by Inclusion Ireland also found that families and professionals report a lack of adequate supports for families caring for a child with a disability.[309]

The Child Care Act, 1991 is not inclusive of children with disabilities and does not adequately protect children in the care of the State

The Child Care Act, 1991, which governs the provision of child welfare and protection services in Ireland is not inclusive of children with disabilities. There is no explicit provision made for the protection and welfare of children with disabilities and part 8 of the Act, which is focused on children's residential centres, explicitly excludes residential centres for children with disabilities. The case of 'Grace' is said to be illustrative of the failures of the State and its Agencies to adequately protect children with disabilities already in the care of the state from harm and abuse.[310] Grace is a young woman with intellectual disabilities who suffered repeat abuse at the hands of her foster carers, when placed in foster care by the HSE as a child. The failings by the State in this case led to questions about the suitability of the Child Care Act, 1991 to protect children already in the care of the State, of which a high proportion, as set out above, have disabilities.[311]

Children's disability services are outside of Tusla's remit

At the time Tusla was established in 2014, the decision was taken to exclude children's disability services from the remit of Tusla. This decision has been criticised by the UN Committee on the Rights of the Child, among other leading authorities.[312] It is consistently reported that their exclusion has resulted in children with disabilities not being able to adequately access all required children and family services.[313] According to

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[306] ibid.

[307] Health Service Executive, *HSE National Service Plan 2019*, (Dublin, 2018).

[308] ibid; Dáil Debate, 10 October 2019, vol 987, no 6.

[309] Inclusion Ireland, 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018).

[310] ibid.

[311] Louise Gibbons, 'What happened to 'Grace'? (Children in State Care)' (familylawinformation.ie, 01 April 2016) <http://familylaw.ucc.ie/2016/04/01/what-happened-to-grace/> accessed 20 October 2020.,

[312] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4); Inclusion Ireland, 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018); Ombudsman for Children's Office, *Molly's case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State* (Dublin, 2018); Geoffrey Shannon, *9th report of the special rapporteur on child protection* (2016).

[313] ibid.

Inclusion Ireland, it has led to a situation where Tusla's staff and Tusla funded agencies, including the Family Resource Centres nationally, are not adequately mandated, resourced and trained to support children with a disability and their families when a child welfare or protection concern arises.[314]

This issue is compounded by a lack of effective inter-agency working. Poor inter-agency working between Tusla and the HSE has been found to have a negative impact on the delivery of services to children with disabilities.[315] An investigation by the OCO into the case of 'Molly', a child in care with a disability, highlighted a lack of co-ordination between the HSE and Tusla and how this resulted in insufficient services and supports being provided by both organisations to a child with disabilities.[316] According to the OCO, the failure of Tusla and the HSE to adequately work together to meet the needs of Molly, and children like her in the care of the State, is resulting in these children not having the opportunity to reach their full potential. It also increases the likelihood of such children being placed in residential care.[317]

At a policy and practice level measures have been taken to improve inter-agency working. At the policy level, the Government is committed to effective inter-agency working in BOBF and other policy documents.[318] In 2017, Tusla and the HSE published a 'Joint Protocol for Interagency Collaboration Between the Health Service Executive (HSE) and Tusla to Promote the Best Interests of Children and Families (the Joint Protocol)'.[319] At a practice level, a range of initiatives have been established to support inter-agency working, such as the Children and Young People Services Committees, Child and Family Support Networks, and Meitheal, a Tusla national practice model.[320]

A recent follow up report tracking progress made on the implementation of the recommendations following the OCO investigation of the case of Molly found that significant progress had been made in improving services and supports for children with disabilities in care, but shortcomings remained in adequately identifying children with disabilities and their needs.[321] While improvements in Interagency cooperation were evidenced after the signing of the Joint Protocol, it was noted further progress and commitment to interagency cooperation is required.[322] Likewise, Inclusion Ireland, has found that their advocacy work has generated anecdotal evidence that the Joint Protocol between Tusla and the HSE is having limited impact and there is little evidence to date on the effectiveness of the inter-agency structures established in terms of

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314 Inclusion Ireland, 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018) 9.

315 Inclusion Ireland, 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018); Ombudsman for Children's Office, *Molly's case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State* (Dublin, 2018)

316 Ombudsman for Children's Office, *Molly's case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State* (Dublin, 2018)

317 ibid.

318 See for example, Department of Children and Youth Affairs, *Children First: National Guidelines for the Protection and Welfare of Children* (Dublin, 2017).

319 Health Service Executive and Tusla, *Joint protocol for interagency collaboration between the HSE and Tusla, child and family agency to promote the best interests of children and families* (Dublin, 2017).

320 Inclusion Ireland, 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018) 11.,

321 Ombudsman for Children's Office, *Molly Two Years On: Have Tusla and the HSE delivered on commitments to children with a disability in the care of the State?* (Dublin, 2020).

322 ibid.

supporting children with disabilities and their families.[323] In June 2020, the Government Department responsible for Tusla, the Department of Children and Youth Affairs expanded its remit to become the Department of Children, Disability, Equality and Integration. The consequence of this change to include governance of disability related matters in a Department responsible for child and youth affairs is, as of yet, unknown.

Overreliance on residential care and inadequate care placements

The Child Care Law Reporting Project reports that more than 90% of children in care are in foster family placements.[324] When the data is disaggregated to take account of children with an intellectual disability, only 50% of children with an intellectual disability are placed in a foster care settings.[325] This is illustrative of a tendency that children with an intellectual disability are more likely to be placed in residential care irrespective of Government policy and their right to a family life.

The Child Care Law Reporting Project shed some light on why this might be the case, noting the views of an experienced Guardian ad Litem, that children with disabilities may have complex needs and can experience more placement breakdowns, as the foster carers may have no experience of children with special needs and there are inadequate supports in place.[326] The inadequacies of supports are further evidenced by the Molly Case set out above. In 2018, Inclusion Ireland stated that the HSE and the Government had failed to deliver the Strategy 'Time to Move on from Congregated Settings - A Strategy for Community Inclusion'. It considered the biggest barrier to the deinstitutionalisation process to have been a lack of leadership from government and from State bodies concerned with health, social care, equality and human rights.[327] Additional barriers included shortage of houses and a lack of professional assessment regarding housing adaptations and renovation costs.[328] Similar barriers were identified by Greene et al. in 2018.[329]

It is also understood that there are children with disabilities are in inappropriate placements.[330] In a case investigated by the OCO in 2016, a child with an intellectual disability was placed in a hospital setting as there was no residential placement available. However, the exact number of such children is not readily available.[331] Children with highly specialised needs, often requiring specialised therapeutic and mental health services, are sometimes placed in specialised care centres abroad. As noted previously by the OCO, at present there is no understanding of the impact of being placed abroad on the children and their family,[332] but it has been identified as a concern by the Committee on the Rights of the Child.[333]

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[323] Inclusion Ireland, 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018) 11.

[324] Carol Coutler, 'Final Report Child Care Law Reporting Project' (Dublin: Child Care Law Reporting Project, 2015).

[325] ibid

[326] ibid 36.

[327] Inclusion Ireland, 'Deinstitutionalisation in Ireland; a failure to act' (Dublin, 2018) 14.

[328] ibid, 19.

[329] Hannah Grene, Stephen O'Hare and Eilionóir Flynn 'From institutions to community living: drivers and barriers of deinstitutionalisation-Case study report: Ireland 2018' (European Union Agency for Fundamental Rights, 2018).

[330] Ombudsman for Children's Office, *Annual Report 2016* (Dublin, 2017).

[331] ibid

[332] ibid.

[333] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4).

Children with disabilities are not visible in National Standards

HIQA's National Standards for Children's Residential Centres 2018[334] apply to all designated children's residential centres — private, voluntary and statutory. However, notably, they are not applicable to designated centres for children with disabilities as these are regulated by the National Standards for Residential Services for Children and Adults with Disabilities.[335] While HIQA's Standards for Residential Care, Foster Care, Special Care and Child Protection and Welfare require services to provide child-centred care and support, describing child-centred services as those 'valuing diversity and inclusion of all groups of children who may be in a minority as a result of their culture, religion, race, ethnicity, sexual orientation, gender identity or disability',[336] little consideration is given to the needs of children with disabilities.

While staff in residential centres are required to communicate appropriately with children according to their development and communication needs, there are no standards specifically focused on children with disabilities. HIQA is currently engaged in the consultation phase of developing an overarching set of national standards for the care and support of children using health and social care services. It is envisaged that these standards will be published in the Summer of 2021.

7.1.3 Measures to overcome identified barriers

Legislative Measures

Reform of the Child Care Act, 1991

According to Inclusion Ireland, while some of the failures of the State to provide appropriate care for children with disabilities in the care of the State are the result of poor operational practices, many could be rectified by reforming the Child Care Act 1991 to be more inclusive of children with disabilities.[337] Inclusion Ireland recommends that the current review of the 1991 Act seeks to ensure that the revised Act is compliant with equality legislation and human rights standards, and thereby is inclusive of children with disabilities. Such a measure would ensure that children with disabilities are granted the same care and protection as all other children.

Similarly, the OCO has recommended that the four general principles of the CRC, including children's right to non-discrimination, should be provided for in the revised Act in a manner that ensures that these principles are mainstreamed as positive obligations in and across all parts of the Act.[338] These revisions of the Child Care Act, 1991 could go some way towards addressing the exclusion of children with disabilities from the remit of Tusla and ensure children with disabilities receive adequate child protection and welfare services. However, to date, no indication has been provided by the Government during the review of the Child Care Act, 1991 consultation phase that

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[334] Health Information and Quality Authority, *National Standards for Children's Residential Centres* (Dublin, 2018) 6.

[335] Health Information and Quality Authority, *National Standards for Residential Services for Children and Adults with Disabilities* (Dublin, 2013).

[336] See for example, ibid 20.

[337] Inclusion Ireland 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018).

[338] Ombudsman for Children's Office, *Department of Children and Youth Affairs: Review of the Child Care Act 1991* (Dublin, 2018).

they intend to include the principle of non-discrimination as a guiding principle.[339]

As part of the review process of the Child Care Act, 1991 calls have also been made to place the requirement of inter-agency working on a statutory footing.[340] While the UN Committee on the Rights of the Child, in its most recent concluding observations on Ireland, did not go so far to recommend legislative measures to place inter-agency working on a statutory footing. The Committee did recommend that measures are undertaken to 'ensure that children in alternative care who have disabilities or mental health needs have those needs addressed in an integrated and comprehensive manner; to that effect, the State party should establish appropriate coordination mechanisms to ensure effective inter-agency cooperation between the State party's Child and Family Agency and the relevant departments of its Health Service Executive'.[341]

Adequate legislative measures must also be taken to facilitate the care of children with disabilities in the home environment. Sweden has been identified as a country that has made good progress towards deinstitutionalisation.[342] During the 1990s legislation made it illegal to care for children in institutions. By 2000 institutional services were eliminated. However, it was found that there was a need to have a small number of residences for short-term care arrangements.[343] It is recommended that the review of the Child Care Act, 1991 must also ensure that when children with disabilities are placed in foster care or residential care, sufficient protection is provided for in the Act to protect these children from harm and abuse while in care.[344]

Administrative and Other Measures

Allocation of Resources

While there is a general view that revisions of the Child Care Act, 1991 could go some way towards addressing the exclusion of children with disabilities from the remit of Tusla and ensure children with disabilities receive adequate child protection and welfare services, other measures have also been identified as important. According to Inclusion Ireland, is it necessary to examine what restructuring and additional funding is required to ensure Tusla is inclusive of children with disabilities.[345]

Resourcing and providing the full range of supports parents of children with disabilities require to support their care giving role (such as parenting courses, home-help, respite) and to support and maintain their mental and physical health is another necessary measure to improve outcomes for children with disabilities. These services may need to be tailored to the individual family's needs. This requires a greater commitment and

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[339] Department of Children and Youth Affairs, Review of the Childcare Act 1991: Consultation Paper (Dublin, 2020).

[340] Inclusion Ireland 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018) 13; Ombudsman for Children's Office, *Department of Children and Youth Affairs: Review of the Child Care Act 1991* (Dublin, 2018)16; Department of Children and Youth Affairs, *A Report on the findings of an Open Policy Debate on the Review of the Child Care Act 1991* (Dublin, 2017).

[341] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4) 9.

[342] Health Service Executive, *Time to Move on from Congregated Settings: A Strategy for Community Inclusion Annual Progress Report 2018* (Dublin, 2018).

[343] ibid.

[344] Inclusion Ireland 'Submission to the Department of Children and Youth Affairs on the review of the Child Care Act 1991' (Dublin, 2018) 20.

[345] ibid.

investment by Government in family support, prevention and early intervention services.

Training and Capacity Building

According to the UN Committee on the Rights of the Child, to ensure there are adequate suitable care placements for children within the State, in particular appropriate foster care placements, there is a need to adequately, recruit, train and support foster parents to care for children with disabilities in a family environment.[346]

Data Generation and Analysis

To address the information gap, there is a need for Tusla to generate and publish data on the number of children with disabilities taken into care, inclusive of all disabilities. Data should also be generated and published on the reason for referral and the number of children with disabilities placed in foster care, residential care and special care.

Development of Indicators/Standards

Given the significant numbers of children in care with a disability, the revision of the HIQA national standards to develop an overarching set of national standards for the care and support of children using health and social care services. should give increased visibility to children with disabilities, with a specific focus on the realisation of their rights.

7.2 Housing

The right to a home offers an integral protection to an individual's privacy, dignity, personal security, and autonomy.[347] The right to adequate housing is provided for in many of the leading UN and European Human Rights Conventions, including the UNCRC and UNCRPD. Article 27 of the UNCRC provides that every child has the right to an adequate standard of living; parents have the primary responsibility to provide this, and the State has a duty to assist parents, where necessary, in fulfilling this right. Article 28 of the UNCRPD also recognises the rights of persons with disabilities to an adequate standard of living for themselves and their families The UN Special Rapporteur on Adequate Housing has recommended that housing strategies 'must ensure that adequate data on programme beneficiaries (process), housing conditions (outcome) and access to justice (structural) is collected and disaggregated by race, ethnicity, disability, age, gender and other relevant characteristics'.[348]

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[346] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4) 10.

[347] Mercy Law Resource Centre 'The Right To Housing In Ireland' (Dublin, 2016) 3.

[348] United Nations General Assembly, Report of the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context (A/HRC/37/53) para.9.

7.2.1 Current Irish Context

7.2.1.1 Profile of children with disabilities

According to latest CSO data from 2016,[349] there were 6871 persons homeless in Ireland. A CSO report disaggregating this data revealed that the proportion of persons with a disability among the homeless population was higher than for the general population. A total of 1,871 homeless persons had a disability, representing 27.1 per cent of the total population, in contrast to the general population where 13.5 per cent of persons have a disability.[350] The Department of Housing, Local Government and Heritage publishes official homelessness data on a monthly basis. These figures are compiled from data collected from local authorities on the number of households accessing local authority managed emergency accommodation. Data contained in these monthly reports is not disaggregated to determine the proportion of persons or children with a disability currently among the homeless population.

7.2.1.2 Overview of law and policy

The Irish Constitution does not include a right to housing. A review of Irish caselaw related to housing starkly highlights that the right to basic shelter or housing is not a right protected in Ireland in either statute or the Constitution.[351] In the case of *C v Galway County Council* the applicant was a lone parent with five children, one with autism and other with severe intellectual disabilities, which required specialised medical treatment.[352] The applicant was evicted from private rented accommodation and placed in emergency accommodation.

When later offered transitional accommodation the applicant refused on the basis that the locality meant that the chid would not be able to access the required specialised medical treatment. Following this refusal the Council withdrew the emergency accommodation. The court gave deference to the Council's decision, noting it would be slow to interfere with such decisions. A commitment is made in the 2020 Programme for Government to hold a referendum on reforming the Constitution in respect to housing.[353]

Housing legislation in Ireland is the responsibility of the Department of Housing, Local Government and Heritage. There are multiple Housing Acts and associated regulations that govern social housing and the regulation of the private rental market. The provision of housing for people with disabilities is the responsibility of a number of Government Departments. The Department of Housing, Local Government and Heritage holds responsibility at the macro level, providing a framework of policy, legislation and funding to underpin the work of local authorities in addressing housing need at local level. The Department of Children, Disability, Equality, and Integration will now also have a brief in this area, with a particular focus on housing for people with disabilities. The Department

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[349] Central Statistics Office, 'Census of Population 2016 – Profile 5 Homeless Persons in Ireland' <https://www.cso.ie/en/releasesandpublications/ep/p-cp5hpi/cp5hpi/nat/> accessed 8 June 2020.

[350] ibid.

[351] Mercy Law Resource Centre, 'Third Right to Housing Report: Children and Homelessness: A Gap in Legal Protection' (Dublin, 2018) 12.

[352] *C v Galway County Council* [2017] IEHC 784.

[353] Government of Ireland, Programme for Government, 'Our Shared Future' (Dublin, 2020) 120.

of Health provides funding to facilitate housing and support for those with a disability.

The National Housing Strategy for People with a Disability 2011 – 2016 was published in October 2011 and the associated National Implementation Framework for this Strategy was published in July 2012.[354] These documents set out the Government's broad policy framework for the delivery of housing for people with disabilities through mainstream housing options. They were developed as part of a coherent framework in conjunction with the Government's policy Time to Move on from Congregated Settings – A Strategy for Community Inclusion. In terms of a child's right to housing in Ireland, BOBF reiterates the government's commitment to adequate housing under the national outcome of 'Economic security and opportunity'. The Government recognises that poverty, sub-standard housing and social exclusion have a significant impact on a person's life outcomes and efforts must be made to reduce the arising inequalities.[355] The quality of a child's housing is strongly linked to their learning outcomes'.[356] To conclude, it is of note that a commitment was made in the current Programme for Government to include disability as a consideration in all future policy reviews.[357]

7.2.2 Key barriers to the realisation of rights

Inadequate Housing

The majority of children reside with family members who can provide adequate housing for them. However, due to the escalating housing crisis this is increasingly not the case. Homelessness and inadequate housing for children has been repeatedly addressed by the CRA since 2015.[358] In 2018, the Alliance reported that for a substantial number of families, 'homelessness occurred alongside other forms of loss and disadvantage including: poverty, domestic violence, bereavement, and disability that presented additional challenges in finding and sustaining accommodation'.[359] The OCO has uncovered that homeless children with disabilities are not afforded any additional priority in the allocation of social housing.[360] According to the OCO, there are children with disabilities waiting for social housing or disability adaptations who are staying in inappropriate emergency accommodation for lengthy periods of time or having to live in a house that has not been adapted to suit their needs.[361] In the cases investigated to date by the OCO, these unsatisfactory situations were not solely as a result of the administrative actions of the local authorities.

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[354] Department of Housing, Planning and Local Government, *Housing for People With A Disability* (Dublin, 2016) <https://www.housing.gov.ie/housing/policy/people-disability/housing-people-disability> accessed 27 April 2020.

[355] Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014-2020* (Dublin, 2014) 87.

[356] ibid 91.

[357] Government of Ireland, Programme for Government, 'Our Shared Future' (Dublin, 2020) 120.

[358] Children's Rights Alliance 'Report Card 2015, 2016, 2017, 2018, 2019, 2020' (Dublin 2015-2020).

[359] Children's Rights Alliance 'Home Works - A Study on Educational Needs of Children Experiencing Homelessness and Living in Emergency Accommodation' (Dublin, 2018) 36.

[360] Ombudsman for Children's Office, *Annual Report 2016* (Dublin, 2016) 36.

[361] ibid 37.

7.2.3 Measures to overcome identified barriers

Legislative measures

As a first step, constitutional or statutory legal protection must be afforded to the right to housing.

Administrative and Other Measures

In 2016, the UNCRC Committee recommended that the State must take measures to address delays in the provision of social housing and to ensure that emergency housing support provided to families who are experiencing homelessness is appropriate to children's needs. They also noted the importance of the State ensuring no disruption to children accessing required services, as a result of changes in a child's accommodation situation.[362] These are measures that are still required to the present day.

7.3 Transport

Under Article 9 of the UNCRPD, the State is obligated to ensure that persons with a disability have the same right, on an equal basis to others, to access transportation. The right to accessibility is also one of the eight General Principles in the Convention[363] and is noted in paragraph V of the preamble.[364] The Committee on the Rights of the Child in its General Comment 9, on children with disabilities, emphasises that the physical inaccessibility of public transport can be a significant factor in the exclusion of children with disabilities and their ability to access required services, including education.[365]

7.3.1 Current Irish Context: Overview of law and policy

As described above in section 6.3.1, the Disability Act 2005 provides the legal basis for obligations in relation to accessibility of the built environment and transport, where these are provided or procured by public bodies. Accessibility to transport also features in the NDIS 2017–2021.[366] The Department of Education and Skills funds school transport and escorts on school transport for children with special educational needs. Children with special educational needs are eligible for school transport where the child is attending their nearest recognised mainstream school, special class/ special school, that is or can be resourced to meet the child's special educational needs. If families choose to send their child to a school further away than the nearest school that can be resourced, school transport is not provided. Eligibility is determined through a complex process, which includes consultation the National Council for Special Education.[367]

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[362] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4) 10, 11 and 13.

[363] UNCRPD, art 3f.

[364] See Accessibility under Section 5: Overarching & cross-cutting rights.

[365] Committee on the Rights of the Child, General Comment 9 – The Rights of Children with Disabilities (2006) para. 39.,

[366] Department of Justice and Equality, *National Disability Inclusion Strategy*, 2017-2021<http://www.justice.ie/en/JELR/Pages/WP17000244> accessed 20 April 2020.

[367] House of the Oireachtas, Joint Committee on Education and Skills, *Report on the Operation of the School Transport Scheme* (November 2018).

7.3.2 Key barriers to the realisation of rights

School Transport

In a report published by the OCO in December 2017, 64 complaints were made regarding school transport. A review of some of these complaints found that 'complex medical needs can be factors, which determine that a child must attend a school that is not the nearest to his or her home'.[368] The need for a more holistic approach, whereby medical and other needs can be factored into a decision on eligibility for school transport, as opposed to the focus being on distance and the school's capability to meet the student's special educational needs, has been highlighted.[369] An Oireachtas Committee Report, on the Operation of the School Transport Scheme, recognised the lack of flexibility in terms of deeming eligibility.[370] The Committee noted that the provision of education for children with special educational needs is a complex issue and schools that fall within the catchment area may not be the best resourced to adequately address all the child's individual needs.[371]

The OCO report also acknowledged particular difficulties for some children with physical disabilities, whereby wheelchair-accessible buses were not available.[372] The Oireachtas Joint Committee on Education and Skills raised additional concerns regarding school transport for children with disabilities. They raised concerns in relation to the lack of autism and other disability awareness training for bus drivers and escorts. Another concern is that, where nurses are required to administer medication on journeys to school, these are not available. There is also no provision to provide transport to and from respite care to school. Lastly, there was the concern that on some routes the journey was deemed to be excessive.[373]

Public Transport

In 2018 the Joint Committee on Transport, Tourism and Sport published a report entitled 'Accessibility of Public Transport for People with Disabilities'.[374] It was published in response to the appearance of witnesses before the Committee articulating the inaccessibility of the Irish public transport system and the disadvantages it poses. While there is no specific focus on children in the report, it identifies a range of common barriers to people with disabilities across the transport system. These include, the requirement to give advance notice of travel, understaffed stations and the limits of the free travel scheme. A range of barriers specific to people with different disabilities, such as autism, visual and hearing impairments were also documented. These include a lack of measures taken for persons with noise sensitivity issues, inappropriate and inadequate signage and modes of communicating announcement and a lack of consideration of the impact of service changes.[375]

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[368] Ombudsman for Children's Office, *School Transport in Focus* (Dublin, 2017) 18.

[369] Ombudsman for Children's Office, *School Transport in Focus* (Dublin, 2017); Houses of Oireachtas 'Report on the operation of the School Transport Scheme November 2018' (Dublin 2018).

[370] Houses of Oireachtas 'Report on the operation of the School Transport Scheme November 2018' (Dublin 2018).

[371] ibid 3.

[372] Ombudsman for Children's Office, *School Transport in Focus* (Dublin, 2017) 18.

[373] Houses of Oireachtas, 'Report on the operation of the School Transport Scheme November 2018' (Dublin, 2018) 17-18.

[374] Houses of Oireachtas, 'Accessibility of Public Transport for People with Disabilities' (Dublin, 2018).

[375] ibid; The full range of barriers identified for diverse public transport users is available at pp. 27-38.

7.3.3 Measures to overcome identified barriers

Administrative and Other Measures

The OCO and the Joint Committee on Education and Skills have recommended flexibility within the School Transport Scheme so that decision makers, when determining eligibility, can take into account all relevant factors to a child's ability to fully participate in and receive an education.[376]

Regarding public transport, the Joint Committee on Transport, Tourism and Sport in their report Accessibility of Public Transport for People with Disabilities, issued 16 key recommendations to 'pave the way towards equal access to public transport services for people with disabilities'.[377] These recommendations included, but were not limited to: the need for planning and decision-making, 'whereby transport requirements of people with disabilities are a core feature of all public transport planning, funding and development'; the need to move towards a fully accessible public transport service across all modes of transport, in terms of accessibility of information and communication of changes to scheduling, the need for a whole journey approach; orientation and way-finding; but also the consideration of service interruptions and clear feedback and/or complaint pathways.[378]

Remedies

In relation to the School Transport Scheme, the OCO previously recommended that 'independent, effective, safe, accessible and child-centred redress mechanisms should be in place to facilitate appealing decisions relating to school transport. Children and their families should be informed about their right to appeal, how to access available redress mechanisms and the follow-up given to any appeal which is lodged, including the relevant professionals involved'.[379]

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[376] Houses of Oireachtas 'Report on the operation of the School Transport Scheme November 2018' (Dublin, 2018) 17; Ombudsman for Children's Office, *School Transport in Focus* (Dublin, 2017) 2.

[377] Houses of Oireachtas 'Accessibility of Public Transport for People with Disabilities' (Dublin, 2018).

[378] ibid 5-11.

[379] Ombudsman for Children's Office, *School Transport in Focus* (Dublin, 2017) 6.

8. Cluster 3 – Health & Welfare

8.1 Right to life, survival and development

The right to life is set out in the UNCRC and the UNCRPD. Article 6 of the UNCRC provides that every child has the inherent right to life and that States shall ensure their survival and development. The Committee expects States to interpret 'development' in its broadest sense as a holistic concept, embracing the child's physical, mental, spiritual, moral, psychological and social development. Implementation measures should be aimed at achieving the optimal development for all children.[380]

Similarly, article 10 of the UNCRPD provides for the inherent right to life and that States shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

In addition to the latter international standards, article 2 of the European Convention on Human Rights protects the right to life, it requires State parties should take appropriate measures to safeguard life by making laws to protect citizens. In some circumstances, this includes taking steps to protect citizens if their life is at risk. It is proposed that public authorities should also have regard for the right to life 'when making decisions that might put citizens in danger or that affect their life expectancy'.[381]

8.1.1 Current Irish Context: Overview of law and policy

Article 40.3.2 of the Irish Constitution recognises the right to life of every citizen and the need to protect this right. This section will address the right to life as it applies to children, once born, in keeping with the jurisprudence of the UNCRPD Committee on the scope of the right to life (as the UNCRC Committee has not yet provided guidance on this matter).[382] Article 6 of the UNCRC is one of the seven guiding principles that apply to all five national outcomes of Better Outcomes Brighter Futures.

Serious incidents and deaths of children

Ireland has a low child mortality rate, with a rate of 3.1 deaths per 1,000 live births in 2018 (the most recent year for which data is available).[383] According to the CSO, in 2018, there were 187 deaths of infants under the age of 1, 27 deaths of children aged 1–4, 54

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[380] UN Committee on the Rights of the Child, General comment no. 5 (2003): General measures of implementation of the Convention on the Rights of the Child (CRC/GC/2003/5).

[381] Equality and Human Rights Commission 'Article 2: Right to life' (15 November 2018) <https://www.equalityhumanrights.com/en/human-rights-act/article-2-right-life> accessed 30 April 2020.

[382] UN Committee on the Rights of Persons with Disabilities, 'Comments on the `Draft General Comment No. 36 of the Human Rights Committee on Article 6 of the International Covenant on Civil and Political Rights' (2019) <https://www.ohchr.org/en/hrbodies/ccpr/pages/gc36-article6righttolife.aspx> accessed 15 October 2020.

[383] United Nations Inter-Agency Group for Child Mortality Estimation, Levels and Trends in Child Mortality (Geneva, 2019).

deaths of children aged 5–14 and 157 deaths of young people aged 15–24.[384] The majority of these deaths (especially in infants under 1) were due to congenital conditions or conditions originating in the perinatal period.[385]

While searching for statistics on deaths of children with disabilities in Ireland, it was identified that, apart from the annual reports provided by the National Review Panel,[386] a breakdown of data on children with disabilities in this regard appears to be missing. While the State of the Nation's Children: Ireland 2016 report[387] provides a compilation of the most up-to-date data, including children with disabilities, from many sources on the National Set of Child Well-being Indicators, the breakdown of numbers on child death and suicide is categorised into gender, age group and cause of death.

This finding corresponds with Mc Carron et al,[388] who argued that the Central Statistics Office maintains data on births and deaths in Ireland, but that there is no variable in this data that identifies whether an individual has a disability. Furthermore, in a review of the deaths of children and young people in state care which occurred between 2000–2010, a report by Geoffrey Shannon and Norah Gibbons investigated 36 deaths during that period of children in care of the State,[389] but this research also does not provide disaggregated data on the numbers of children with disabilities who died in the care of the state.[390]

Suicide Prevention

According to the WHO, twenty per-cent of the world's children and adolescents have mental health problems and suicide is the second leading cause of death in 15 to 29 year olds.[391] In Ireland we have had a high rate of youth suicide and it was the leading cause of death among adolescents.[392] Ireland has the fourth highest suicide rate across Europe in the 15 to 19 age group.[393] The Irish government has promised to achieve better outcomes for all children and young people by strengthening efforts to implement their rights and enhance their mental well-being.[394]

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[384] Central Statistics Office, *Vital Statistics 2018 – Births, Deaths and Marriages* (Dublin, 2019).

[385] ibid.

[386] National Review Panel (2020) <https://www.tusla.ie/national-review-panel/> accessed 3 May 2020.

[387] Department of Children and Youth Affairs, *The State of the Nation's Children: Ireland 2016* (Dublin, 2016).

[388] Mary McCarron, Rachael Carroll, Caraiosa Kelly and Philip McCallion 'Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012' (2015) 28(5) Journal of Applied Research in Intellectual Disabilities 408.

[389] Geoffrey Shannon and Norah Gibbons, 'Report of the Independent Child Death Review Group' (Dublin: Department of Children and Youth Affairs, 2012) vi and x.

[390] ibid 71-74.

[391] World Health Organization, Factsheet on Mental Health: Facts 1 and 3 <http://www.who.int/features/factfiles/mental_health/en/> accessed 20 October 2020.

[392] Health Service Executive, *Fifth Child and Adolescent Mental Health Service Annual Report 2012/2013* (Dublin, 2013); Health Service Executive, *National Office for Suicide Prevention Annual Report* (Dublin, 2013).

[393] National Office for Suicide Prevention, *Connecting for Life 2015-2020: Ireland's National Strategy to Reduce Suicide 2015-2020* (Dublin: Health Service Executive, 2015).

[394] Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People* 2014-2020 (Dublin, 2014) viii, x.

The national strategy on suicide, Reach Out: The National Strategy for Action on Suicide Prevention 2005 – 2014, ended in 2014. While much progress was made, the Children's Right Alliance argues a weakness in the Strategy's implementation in a fragmented way, with services being rolled out in an *ad hoc* manner across certain areas of Ireland rather than adopting a strategic approach.[395] In June 2015, the Government launched a follow-on national strategy, Connecting for Life – Ireland's National Strategy to Reduce Suicide 2015–2020.[396] The Strategy contains a range of commitments dedicated to children and young people. Key commitments include the implementation of relevant guidelines for mental health promotion and suicide prevention in schools; and a commitment to train those working in child protection services to deliver suicide prevention.[397]

In the Interim Strategy Review of Connecting for Life,[398] some positive developments in relation to children were noted, including cross-departmental co-operation and commitment to the strategy between the Department of Health and the Department of Children and Youth Affairs.[399] However, challenges were also identified in progressing the strategy's objectives for children and young people, including the failure to roll out access to psychological services for children as a suicide prevention mechanism.[400]

8.1.2 Key barriers to the realisation of rights

Lack of data on serious incidents and child deaths

A breakdown of data on children with disabilities in this regard appears to be missing. While the National Set of Child Well-being Indicators provides a breakdown of numbers on child death and suicide it is categorised into gender, age group and cause of death. There is no variable in this data that identifies whether a child has a disability.

Slow progress on implementation of suicide strategy

Enhancement of accessibility, consistency and care pathways of services for people vulnerable to suicidal behaviour were noted as making limited progress[401] as was the commitment to ensure safe and high-quality services for people vulnerable to suicide.[402] While progress is evident in the attention given to mental health at a public policy level, it is now necessary that urgent action be taken to drive implementation of the actions set out in the Connecting for Life Strategy to reduce suicide in Ireland. 'Sharing the Vision', Ireland's revised strategy for mental health, published in June 2020, reaffirms the recommendations of the Connecting for Life Strategy and also acknowledges the need for further, accessible specialised mental health supports for children and young people, but does not make any additional recommendations in respect of children with regard to suicide prevention.[403]

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[395] ibid 26.

[396] National Office for Suicide Prevention, *Connecting for Life 2015-2020: Ireland's National Strategy to Reduce Suicide 2015-2020* (Dublin: Health Service Executive, 2015).

[397] Children's Rights Alliance, 'Are we there yet? Parallel Report to Ireland's Third and Fourth Combined Report under the UN Convention on the Rights of the Child' (Dublin, 2015) 26.

[398] National Office for Suicide Prevention, *Interim Strategy Review- Connecting for Life: Ireland's National Strategy to Reduce Suicide 2015-2020* (Dublin, 2019).

[399] ibid, 22.

[400] ibid, 30.

[401] ibid, 16.

[402] ibid, 17.

[403] Department of Health, *Sharing the Vision: A Mental Health Policy for Everyone* (Dublin, 2020) 38.

8.1.3 Measures to overcome identified barriers

Administrative and other measures

Targeted approaches are needed to increase access to services for children at risk of suicide, including a national roll-out of Access to Psychological Services Ireland, a suicide prevention tool already in place for adults.[404]

Further data collection on deaths of children with disabilities is required in order to inform evidence-based policy to protect the right to life. For example, any further reviews conducted into the deaths of children in the care of the state, should specifically include disaggregated data on the deaths of children with disabilities.[405]

8.2 Health

The right to the highest attainable standard of health is found in a number of human rights instruments.[406] The right to health is a socio-economic right and therefore it calls on governments to progressively achieve the realisation of this right.[407] While this is a progressive obligation to fulfil rights contained in the relevant Conventions,[408] State Parties are required to take immediate action with targeted measures to achieve the right to health.[409]

Health is mentioned on several instances in the UNCRC. Article 3(3) calls upon State Parties to ensure that institutions and facilities for the care of children adhere to health standards established by competent authorities. Article 17 recognises the child's right to access information that is pertinent to the promotion of his/her physical and mental health and well-being. Article 23 makes specific reference to the rights of disabled children, in which it includes effective access, subject to available resources and resources of parents, to health care services and rehabilitation services.[410] Article 24 outlines that 'State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States shall strive to ensure that no child is deprived of his or her right of access to such health care services.'[411]

Article 25 of the UNCRPD specifies that 'persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.' The sub-clauses of article 25 state that States shall give persons with disabilities the same 'range, quality, and standard' of health care as it provides to other persons, as well as those services specifically required for prevention, identification, and management of disability. Further provisions specify that health care

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[404] National Office for Suicide Prevention, *Interim Strategy Review- Connecting for Life: Ireland's National Strategy to Reduce Suicide 2015-2020* (Dublin, 2019) 30.

[405] Geoffrey Shannon and Norah Gibbons, 'Report of the Independent Child Death Review Group' (Dublin: Department of Children and Youth Affairs, 2012) 71-74.

[406] UNCRPD, art 25; UNCRC art 24; International Covenant on Economic Social and Cultural Rights, art 12; Universal Declaration of Human Rights, art 25.

[407] UNCRC, art 4; UNCRPD, art 4(2).

[408] ibid.

[409] UN Committee on the Rights of the Child, General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24) (CRC/C/GC/15), para 72.,

[410] UNCRC, art 23.

[411] UNCRC, art 24.

for disabled people should be made available in local communities and that care should be geographically equitable, with additional statements against the denial or unequal provision of health services on the basis of disability.[412] In addition, article 25(d) of the UNCRPD provides that State parties require 'health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care'.

If the rights of children with disabilities are to be made real, State Parties will have to consider the universality and interdependence of civil and political rights and economic, social and cultural rights. One way this can be achieved is through the link established in the UNCRPD between non-discrimination and providing reasonable accommodation.[413] Additionally the principles of accessibility and participation in the UNCRPD are important tools for breaking down barriers to the realisation of the right to health for children with disabilities.[414]

8.2.1 Current Irish Context

8.2.1.1 Profile of children with disabilities

The Health Research Board databases NIDD and NPSDD were merged in 2017 into the National Ability Support System to provide information on the number of adults and children with disabilities and in receipt of disability services. Consequently, these databases do not capture those who are on waiting lists for services or those waiting to have an Assessment of Need, and are in general more focused on services for adults with disabilities.[415] In September 2020, the HRB published a report from the merged databases indicating that in 2019, there were 6,452 children with disabilities in receipt of disability services (this includes children with intellectual disabilities, autism, developmental delay, mental health issues, physical and sensory disabilities).[416]

In 2018, HIQA published figures on the number of places for children with disabilities in designated residential centres for people with disabilities. It reported that in October 2018, there were 320 places for children and a further 287 placements for either adults or children.[417] According to a 2017 Seanad Public Consultation Committee Report, it is estimated that 115,000 children in Ireland have a mental health illness, causing some impairment, and 23,000 children have severe and disabling mental health problems.[418] According to the Mental Health Commission, the number of children receiving in-patient psychiatric treatment in 2019 (the most recent year for which figures are available) was

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[412] UNCRPD, art 25.

[413] See section 5.1 above.

[414] ibid.

[415] Health Research Board, Latest Disability Data (2017) <https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/latest-data/> accessed 14 October 2020.

[416] Claire Casey, Michael O'Sullivan, Sarah Fanagan and Anne Doyle, 'National Ability Supports System Bulletin 2019' (Dublin: Health Research Board, 2020).

[417] Health Information and Quality Authority, *Five years of regulation in designated centres for people with a disability* (Dublin, 2019) 17.

[418] Houses of Oireachtas, *Seanad Public Consultation Committee Report on Children's Mental Health Services* (Dublin, 2017) 17.

497 (increased from 408 in 2018).[419] The same report notes 54 of these children detained on adult wards, although 23 of these admissions were for less than 48 hours.[420] Jigsaw notes in its Annual Report 2018 (the most recent year for which an annual report has been published) that it provided mental health support services to 6,356 children and young people aged 12–25.[421] No further breakdown of this figure is available including the proportion of people under 18 who benefitted from Jigsaw's support services.

Investment in health care for children with disabilities

The total budget allocated to the Department of Health for 2019 was €17 billion.[422] The most recent HSE annual report and financial statement 2018 does not provide a breakdown of funding allocated to children with disabilities. However, there are some examples of health funding which has been ringfenced for children with disabilities. In 2017 the Government announced the allocation of €10 million to provide a medical card to all children who qualify for the Domiciliary Care Allowance.[423] The Allowance is a monthly payment for children under the age of 16 with a severe disability, and approximately 9,000 extra children were expected to benefit from the measure.

The Sláintecare report acknowledged that it 'had not done any detailed analysis of needs in the disability area, but recommended earmarking of €290 million expansion over a ten-year period, on top of the current allocation provided for disability services'.[424] There is a clear lack of data regarding budgetary allocations and the cost of services specifically for children with disabilities. There are a number of reports projecting or forecasting costs for healthcare in Ireland; however, they do not adequately cover the costs of disability health and social care services.[425] The Transforming Lives report provides estimates of funding required by the disability services programme with no identified costs for delivery of child-specific services.[426] Most of the estimates are based on data in the National Intellectual Disability Database, where the data focuses more on adults than on children.

In Budget 2019, there was an increase in funding for mental health services, however the exact allocation to the Child and Adolescent Mental Health Services (CAMHS) was unclear.[427] The CRA report notes that 'expenditure measures announced included an additional €55 million to continue the development of mental health services, particularly community services'.[428]

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[419] Mental Health Commission, *Annual Report 2019, Including Report of the Inspector of Mental Health Services* (Dublin, 2019) 27.

[420] ibid 5.

[421] Jigsaw, 'Annual Report: Delivering Services' (Dublin, 2018).

[422] Children's Rights Alliance 'Budget 2019 - What does it mean for Children and Young People?' (Dublin, 2018).

[423] Health (Amendment) Act 2017, s2.

[424] Houses of Oireachtas, *Committee on the Future of Healthcare Sláintecare Report* (Dublin, 2017) 65.

[425] The Economic and Social Research Institute, *Projections of Demand for Healthcare in Ireland 2015-2030* (Dublin, 2017); The Economic & Evaluation Service's report 'Budgetary Impact of Changing Demographics 2016-2026' (2016) and HSE's Planning for Health 2017 discusses some of the forecasts from the NIDD, but does not provide any estimates of the cost of future additional demand for residential disability services.

[426] Transforming Lives Working Group 1, *Report on Future Needs for Disability Services* (Dublin, 2018) 45.

[427] Children's Rights Alliance 'Budget 2019 - What does it mean for Children and Young People?' (Dublin, 2018) 4.

[428] ibid 5.

8.2.1.2 Overview of law and policy

The public health care system is governed by the Health Act 2004, which established the HSE, responsible for providing health and personal social services to everyone living in Ireland. The HSE came officially into being on 1 January 2005. As outlined in the Health Act, 2004 the 'objective of the Executive is to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public'.[429]

In 2017, the Oireachtas Committee published Sláintecare, outlining proposals for a ten-year strategy for the transformation of health care and health policy in Ireland. The Committee's agreed vision was for a universal single-tier health and social care system where everyone has equitable access to services based on need. The vast majority of care should be provided in primary and community settings and key recommendations included the expansion of capacity in primary care and social care - meaning, among other areas, investment in community diagnostics, primary care teams and mental health teams, services for people with disabilities, homecare services and free GP (General Practitioner) care.[430]

Unfortunately, the Strategy does not contain any new measures to increase access to primary care for children with disabilities. The Sláintecare Report 2017,[431] acknowledges that further work is needed to cost universal services for people with disabilities, but there is no reference to children with disabilities specifically in this context. The Sláintecare Action Plan 2019 is a welcome development as a key plan is to ensure the provision of healthcare services in local communities. However, planning for access to these services must clearly indicate how children with disabilities will access them on an equal basis with other children. Long waiting lists for health and social care services have become a major issue, particularly for children with disabilities.

Promoting positive mental health and well-being across the lifespan for everyone is a key objective in the Irish government's national policy on mental health. On 17th June 2020 the Department of Health launched the long awaited successor to A Vision for Change: 'Sharing the Vision' A Mental Health Policy for Everyone. Sharing the Vision brings forward elements of A Vision for Change that remain relevant for mental health services in 2020, including a holistic person-centred and recovery- oriented approach. The Vision of the new policy is one of service integration in the community, early intervention, inclusion and recovery.[432] The policy advocates a human rights approach, recognising that at the core of Ireland's international obligations is the fulfilment of civil, political, economic and social rights for all people.[433] It incorporates new recommendations and aligns itself with the Sláintecare report for reform and transformation of Ireland's health and social care services.

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[429] Health Act 2004, section 7.

[430] Houses of Oireachtas, 'Press Release: Future of Healthcare Committee publishes Sláintecare – a plan to radically transform Irish healthcare' (30 May 2017) <https://www.oireachtas.ie/en/press-centre/press-releases/20170530-future-of-healthcare-committee-publishes-slaintecare-a-plan-to-radically-transform-irish-healthcare/> accessed 4 May 2020.

[431] Houses of Oireachtas, *Committee on the Future of Healthcare Sláintecare Report* (Dublin, 2017).

[432] Health Service Executive, *Sharing the Vision* (Dublin, 2020) 17.

[433] ibid.

The National Disability Inclusion Strategy (NDIS) 2017–2021 includes a theme on health and well-being to ensure people with disabilities, including children, are supported to reach the best possible physical, mental and emotional well-being.[434] The theme sets out key actions to be taken including investment in early intervention services which specifically target the mental health needs of children, and to examine the need for statutory advocacy services for children with mental health difficulties.[435] However, there are no measurable targets, deliverables or timeframes set out in order to achieve these actions.

In 2018, the Government launched a ten year, cross-government strategy called First 5: A Whole-of Government Strategy for Babies, Young Children and their Families. The strategy includes specific objectives aimed at ensuring that therapeutic and medical provision is available to babies and young children on a consistent, equitable and timely basis, and that babies, young children and their families enjoy positive mental health.[436]

Provision of health and social care services for children with disabilities

Disability services in Ireland are delivered by the HSE, and voluntary service providers funded by the HSE. The HSE is responsible for the provision of a number of services, including health services, assessment for services, community care, rehabilitation, residential and day care. Services have developed independently over time leading to wide variation in the services available and in the approach to assessment of need in different parts of the country and for different categories of disability.[437] Currently, the main HSE funded service requirements for children with disabilities are therapy services, including early intervention and respite care. In addition, there is demand for mental health services and often children requiring these services have dual diagnosis of mental health difficulties and autism.[438]

There are a number of laws,[439] policies and programmes[440] relevant to ensuring the provision of health and social care services to children with disabilities. The Disability Act 2005 was one element of the former National Disability Strategy 2004, aimed at the equitable provision of disability services. The Disability Act 2005 forms part of the statutory framework for access to disability services. The 2005 Act defines ‘disability’ as a ‘substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment’.[441]

Part 2 of the 2005 Act provides for independent assessment of needs (AON) of people

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[434] Department of Justice and Equality, *National Disability Inclusion Strategy 2017-2021* (Dublin, 2017) 11

[435] ibid, 30.

[436] Government of Ireland, *First 5 – A Government Strategy for Babies, Young Children and their Families 2019-2028* (Dublin, 2019).

[437] See National Disability Authority, *Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005* (Dublin, 2011).

[438] Transforming Lives Working Group 1, *Report on Future Needs for Disability Services* (Dublin, 2018) 45.

[439] These include Education for Persons with Special Education Needs Act 2004; Disability Act 2005 and Children First Act 2015.

[440] Health Service Executive, *National Policy on Access to Health Services for Children with Disability or Developmental Delay* (Dublin, 2019); Health Service Executive, *Progressing Disability Services for Children and Young People Programme* (Dublin, 2011).

[441] Disability Act 2005, s2.

with disabilities.[442] The purpose of the AON is to determine the health or education need for services, if any, required by the disability.[443] Following the assessment of need, a Service Statement is prepared detailing the services which are needed and the timescale for delivery of these services. Importantly, there is no right to the services outlined in the Service Statement. All services will be provided within current resources and, due to this limitation, disability organisations believe the 2005 Act is an inadequate piece of legislation which fails to meet the needs of people with disabilities.[444] As a consequence of this some children and their families have little or no access to services. In addition, there is a gap between service needs and actual service provision.

It is well documented that early identification and intervention are key for children to reach their development potential.[445] The current assessment of need system has been found by the Ombudsman for Children's Office to be inadequate in providing early intervention, and the system focuses very much on diagnosis of disability.[446] HIQA have published standards for the assessment of need,[447] and failure to comply with these standards can initiate a complaints process to the HSE. However, the National Disability Authority have found that these standards have not been effective for use in practice and require updating.[448]

In the last 10 years there has been a significant effort by the HSE to develop dedicated national policies with regard to disability services for children. The HSE's work in this field can be found within Progressing Disability Services for Children and Young People,[449] a key component of the Transforming Lives programme, which covers policy relating to both adult and children's disability services.

The vision of the programme is that every child or young person with a disability will be supported to achieve their full potential through the implementation of an integrated service model that will allow children, whatever the nature of their disability, to be seen and supported as locally to their home and school as possible based on their needs, moving away from a focus on diagnosis as the trigger for supports. It is envisaged that once all Children's Disability Network Teams are in place there will be full national cover by the end of 2020.[450] Children's Disability Network Teams are to provide an integrated model that reconfigures the existing inconsistent and varied disability services

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[442] Currently children born after 1st of June 2002 can apply for an assessment of need under the Disability Act 2005 as a result of the High Court's decision in *Health Service Executive v Dykes* [2009] IEHC 540. As of the 1st of June 2018, young persons aged over 16 can also apply.

[443] Disability Act 2005, s7.

[444] See, Carl O'Brien, 'Disability Bill totally flawed, support group says' *The Irish Times* (Dublin, 7 May 2005).

[445] Ombudsman for Children's Office, *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (Dublin, 2020); J.F. v H.S.E.; K.K. v H.S.E. [2018] IEHC 294; Joint Oireachtas Committee on Health, *New Standard Operating Procedure for Assessment of Need under the Disability Act 2005: Discussion* (June 2018); UN Committee on the Rights of the Child, General comment No. 7 (2005): Implementing Child Rights in Early Childhood, (CRC/C/GC/7/Rev.1) para 6.

[446] Disability Act 2005, s14.

[447] Board of the Interim Health Information Quality Authority, Standards for the Assessment of Need (May 2007) <https://www.hse.ie/eng/services/list/4/disability/disability-assessment/standards-for-need-assessment.pdf> accessed 20 October 2020.

[448] National Disability Authority, *Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005* (Dublin, 2011) 66.

[449] Health Service Executive, *Progressing Disability Services for Children and Young People (PDS)* (February 2020).

[450] Health Service Executive, *Progressing Disability Services for Children and Young People (PDS)* (February 2020) 19.

across the country with a focus on person-centred primary and community services. However, this has not been achieved to date as each county is at a different stage in reconfiguration.

In line with this integrated service model a performance reporting system for programme accountability of multi-disciplinary (and often, multiagency) children's disability teams was developed, which is focused on outcomes for children with disabilities and their families.[451] This system resulted in the Outcomes Focused Performance Management and Accountability Framework 2013.[452] The framework has six outcomes statements for children and young people with disabilities, including that they have the best possible health, and can take part in home, school and community life.[453] Each outcomes statement has a set of goals and indicators to measure success in meeting the outcome for the child and young person. While the framework was to begin implementation in 2018, there are no published reports monitoring the implementation this framework to date.

The National Policy on Access to Health Services for Children with Disability or Developmental Delay was published by the HSE in 2019. This policy has been designed to ensure greater consistency throughout the country regarding access to Primary Care and Children's Disability Network Teams.[454] The policy is due for review and revision by December 2021, but at the time of writing, no progress reports on its implementation have been published by the HSE.

According to the Government's Draft Initial State Report on the CRPD, the HSE has now established a cross-departmental Autism Assessment and Pathways Project which seeks to develop an operational model for a tiered approach to autism assessment, to identify clear and functioning pathways to services and develop training materials to support the agreed standardised assessment approach.[455] The project's goal is to provide information to service providers and the public about the experience of people with autism. The Draft Initial State Report notes that the project board includes an autistic person and a parent of an autistic person,[456] but no further information is available about the membership of the board of the work of the project on the HSE's website at the time of writing. While this initiative seems to be geared towards developing more national consistency in approaches to autism diagnosis and assessment, which is important for children with disabilities, it appears to be early on in this work and it is not clear to what extent the project has achieved these goals.

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[451] Health Service Executive and Mary Immaculate College, Limerick, 'Working Together to Support Children and Young People with a Disability and their Families, Conference Report' (2018). <https://www.hse.ie/eng/services/publications/disability/progressing-disability-services-for-children-and-young-people-conference-report-2018.pdf> accessed 20 October 2020.

[452] Health Service Executive, *Outcomes for Children and their Families-Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams* (2013) <https://www.hse.ie/eng/services/list/4/disability/progressing-disability/report-on-outcomes-for-children-framework.pdf> accessed 4 May 2020.

[453] ibid, 5.

[454] Health Service Executive, *National Policy on Access to Health Services for Children with Disability or Developmental Delay* (Dublin, 2019) 3.

[455] Department of Children, Equality, Disability, Integration and Youth, *Draft Initial Report under the Convention on the Rights of Persons with Disabilities: Ireland* (Dublin: December 2020), 43.

[456] ibid, 43.

Child and Adolescent Mental Health Services (CAMHS)

Mental health care and treatment for children is delivered through the HSE CAMHS. The HSE is charged with reporting annually on the progress of CAMHS. Unfortunately, the HSE has not published an annual report since 2013, which is a major barrier to understanding the provision and progress of mental health services for children. The annual reports provided a comprehensive update on the development of services for children, outlined progress in line with A Vision for Change, and reported important information on the number of new cases, waiting times for appointments, and the types of mental health problems presenting to services, by age and gender. Due to non-publication of this report for seven years, there is a large gap in knowledge and data on children with mental health problems in Ireland.

Further to this, the HSE is responsible for developing policies and procedures to guide health professionals in their functions and for the effective delivery of health services. Of particular interest is the HSE National Consent Policy, which offers guidance for health professionals when considering how to gain a valid consent for the treatment of children and young people.[457] The consent policy, while aimed at general health care, provides a section covering issues of capacity and consent for mental health treatment.[458] In addition, the HSE has developed a CAMHS Operational Guideline, the purpose of which is to ensure the delivery of CAMHS reflects the clinical needs of children and is consistent across the country.[459]

CAMHS operates under a tiered model including primary care, community care, inpatient and forensic care. Primary care includes access to GP, counselling, or Jigsaw[460] services for children with mild mental distress. Community CAMHS are delivered in outpatient and day care settings as close as possible to where the person lives. A child must have a moderate to severe ‘mental disorder’ to receive interventions by Community CAMHS. This approach to intervention is unfortunate as it creates a diagnostic access route to support and intervention in the community. It highlights how this system operates under the medical model of disability which is contrary to the UNCRPD. Under the tiered model the tertiary service provides forensic and inpatient care and treatment for those children with complex and severe ‘mental disorder’.

The terms mental health problem, mental health difficulties, mental distress or alternatively psycho-social disability are used in this report to encompass legally defined terms such as mental illness and mental disorder.[461] While the HSE and the World Health Organisation (WHO) use the term mental disorder, disability rights literature, including the voices of people with psycho-social disability or mental distress, prefer the latter terms. Disorder is a medically based term which fits within the medical model of disability and fails to encompass the psycho-social elements of mental distress or the social and human rights model of disability.

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[457] Health Service Executive, *National Consent Policy* (Dublin, 2019).

[458] ibid.

[459] Health Service Executive, *Child and Adolescent Mental Health Services Operational Guideline Second Edition* (Dublin, 2019).

[460] See Jigsaw, ‘Jigsaw – The National Centre for Youth Mental Health’ <https://www.jigsaw.ie/> accessed 20 October 2020.

[461] In this context, the term ‘mental health problem’ is used by organisations such as Mental Disability Advocacy Centre, European Union Agency for Fundamental Rights and Amnesty International Ireland. The term was the preferred term of the majority of the Experts by Experience Advisory Group, which guided Amnesty’s work, see ‘Mental Health Act 2001: A Review’ (Dublin: Amnesty International, 2011) 10.

It is well documented that CAMHS is underdeveloped.[462] To operate effectively it is estimated that 107 specialist teams are needed for CAMHS. Latest figures from the CRA Report Card 2020[463] suggest that CAMHS received 13,719 referrals from January to September 2019 where 70 per cent of these referrals were seen within 12 weeks and 95 per cent seen within one year.[464] As noted by the Ombudsman for Children's Office,[465] waiting lists for Child and Adolescent Mental Health Services (CAMHS) remain high, with 2,300 children waiting for an appointment at end of December 2019.[466]

Inpatient care and treatment

In Ireland, the Mental Health Act 2001 (MHA 2001) provides the statutory framework for the admission and treatment to inpatient care for children with mental health difficulties. A child is defined in the MHA 2001 as a person under the age of 18 years.[467] While the Mental Health Amendment Act 2018 has passed and contains some new guiding principles for children with respect to inpatient mental health, this has not been commenced at the time of writing, and further amendments to the 2001 Act would be required to give effect to the recommendations of the Expert Group on the Review of the Mental Health Act in respect of child in-patients. According to the Autumn Legislative Programme 2020, a further Mental Health Amendment Bill is being developed to give effect to the recommendations of the Expert Group and the status of this new Bill is 'Final Heads in Preparation'.[468] The Programme for Government 2020 also contains some specific commitments in terms of child mental health as follows:

- Work to end the admission of children to adult psychiatric units by increasing in-patient beds, as well as examining the model of assigning these beds.
- Continue to support the expansion of Jigsaw services and their existing network of early intervention and prevention services and supports.
- Implement the Pathfinder inter-departmental unit on youth mental health.
- Complete the update of the 2001 Mental Health Act, including amendments to allow young people, aged 16-17 years old, the right to consent to treatment for their mental health.[469]

This section of the report considers the care and treatment of children in inpatient CAMHS.[470] The liberty and security section of this report will consider specifically the issue of detention and deprivations of liberty under mental health law.[471]

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[462] Health Service Executive, *Child and Adolescent Mental Health Services Operational Guideline Second Edition* (Dublin, 2019); Mental Health Reform, 'Mental Health Reform continue to be seriously concerned about the waiting for CAMHS' (Mental Health Reform, 24 August 2019) <https://www.mentalhealthreform.ie/news/mental-health-reform-continue-to-be-seriously-concerned-about-the-waiting-for-camhs/> accessed 20 October 2020.

[463] Children's Rights Alliance, 'Report Card 2020' (Dublin 2020).

[464] Communication received by the Children's Rights Alliance from HSE Mental Health Services, 30 January 2020.

[465] Ombudsman for Children's Office, *Submission to the UN Committee on the Rights of the Child on the List of Issues Prior to Reporting for the fourth periodic examination of Ireland* (Dublin, 2020).

[466] Dáil Debate 5 March 2020, vol 992, col 882.

[467] Mental Health Act 2001, s2.

[468] Office of the Government Chief Whip, Legislation Programme: Autumn Session (2020) 18.

[469] Government of Ireland, Programme for Government, 'Our Shared Future' (Dublin, 2020) 53- 54.

[470] For data on the number of children currently in in-patient CAMHS, see section 4 above.

[471] See section 10.1.1.2 of this report on Liberty and Security .

It is clear from article 1 of the UNCRPD and the Preamble that persons with disabilities include persons with mental health problems.[472] Consequently, the rights of children with mental health problems or mental distress are disability rights and protected under the UNCRPD.[473]

The admission of children to inpatient CAMHS invokes a number of human rights concerns for the implementation of the right to the highest attainable standard of health. These concerns are due to the very nature of mental health care and treatment. Mental health laws are set up to regulate when society can place restrictions on an individual's rights when this is necessary in the interest of the individual or to protect the public interest. This approach provides for coercive interventions, like forced treatment, and as such mental health law must provide safeguards to balance against deprivations or restrictions of human rights.

Concerns about the human rights of children in inpatient CAMHS have also been raised in 'Take My Hand', a report published by the Ombudsman for Children's Office in 2018. To develop the report's findings, researchers worked with 25 young people aged 14–17 who were receiving treatment in 5 different CAMHS settings.[474] The young people highlighted the changes they wanted to see, and raised concerns about restrictive practices, including the use of physical restraint in inpatient CAMHS units.[475] Recommendations for change included providing greater autonomy to children in inpatient care including less restrictions on freedom of movement within the units, more autonomy to self-regulate and fewer restrictions relating to items that comfort or distract young people.[476]

Provision of services between primary care, disability and mental health

There are a number of joint working protocols in place with the aim of ensuring seamless service delivery and clarifying roles and responsibilities. The Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services 2017 provides that a co-operative culture between Primary Care, Disability and Child and Adolescent Mental Health Services must be promoted, based on clarity of roles and responsibilities and a collaborative approach to service delivery. This was in response to acknowledging that services in some areas had not yet evolved to a stage where the National Policy on Access to Services for Children and Young People with Disability and Developmental Delay and the CAMHS Standard Operating Procedure (2015)[477] can fully and effectively be implemented.[478]

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[472] See also the interpretation given to 'persons with disabilities' by Mental Disability Advocacy Centre: All people with disabilities, which by definition includes people with intellectual disabilities and people with mental health problems, have the right to 'enjoy legal capacity on an equal basis with others in all aspects of life' (Article 12(2) UNCRPD, see http://www.mdac.info/en/content/welcome-first-edition-mdac's-quarterly-e-newsletter).

[473] Phil Fennel, 'Human Rights, Bioethics and Mental Disorder' (2008) 27 Medicine and Law 95; UNCRPD, arts, 1, 3, and 7;

[474] Ombudsman for Children's Office, *A Report by the Ombudsman for Children's Office 2018, Take my Hand: Young People's Experiences of Mental Health Services* (Dublin, 2018) 7.

[475] ibid 41.

[476] ibid 48.

[477] This has been updated in 2019, see Health Service Executive, *Child and Adolescent Mental Health Services Standard Operational Guidelines* (Dublin, 2019).

[478] Health Service Executive, Joint Working Protocol Primary Care, Disability and Child and Adolescent Mental Health Services (Dublin, 2017).

8.2.2 Key barriers to the realisation of rights

Access to services for children with disabilities

There is no comprehensive statutory framework to ensure that children with disabilities have the right to access and enjoy a full range of health and social care services; this is contrary to articles 3, 23 and 24 of the UNCRC and articles 3, 7 and 25 of the UNCRPD.[479] The UN Conventions oblige State Parties to take action to ensure health services are available, affordable and accessible.[480] The proportion of complaints received by the OCO relating to health services has decreased from 16% in 2018 to 14% in 2019.[481] Between 2017 and 2019, the Ombudsman for Children's Office received 95 complaints from parents regarding access to Assessment of Need (AON).[482] In the Ombudsman for Children's Office Annual Report 2019,[483] children's stories underlined that progress still needs to be made to ensure equality for children with disabilities in Ireland. The Ombudsman for Children's Office raised concern about the impact that delays in accessing both an AON and the subsequent services is having on children with disabilities. Children with disabilities need to be assessed as quickly as possible to ensure they receive appropriate care and services based on need.

The current mechanism in the Disability Act 2005 is not effective in achieving early identification and intervention. The 2005 Act does not align with the concept of disability nor the human rights approach to disability in its attempt to provide access to health services.[484] The evolution of national policies and programmes aimed at guiding implementation of access to services indicate a shift to needs rather than diagnosis. This policy approach is closer to the underlying philosophy of the UNCRPD, particularly the shift from a medical based model to the human rights based model of disability. However, despite the numerous policies and programmes developed around access to services for children with disabilities, the aims of these measures are not being fully achieved.

The main reasons for this are an inadequate legislative framework and insufficient resources allocated to meet demand for services.[485] These inadequacies deny children with disabilities access to available, affordable, quality healthcare. The latter issues are of serious concern given that early intervention, in particular for children with disabilities, is critical to help a child reach their full potential.[486] As outlined above in this report, development is to be interpreted in the broadest sense to include mental, emotional, cognitive, social, physical and cultural development. Survival and development rights require the government to provide resources and access to the means necessary to fulfil these rights.

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[479] Children's Rights Alliance, 'From Rhetoric to Rights', (Dublin, 2006) 41.

[480] UNCRC art 24; UNCRPD art 25; see also UN Committee on the Rights of the Child, General comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24) (CRC/C/GC/15) 8.

[481] Ombudsman for Children, *Annual Report 2019* (Dublin, 2020) 49.

[482] Ombudsman for Children's Office, *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (Dublin, 2020) 5.

[483] Ombudsman for Children, *Annual Report 2019* (Dublin, 2020) 8.

[484] See section 8.2.1.2 above.

[485] Ombudsman for Children's Office, *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (Dublin, 2020) 9.

[486] UNCRC art 6; see also Children's Rights Alliance, 'Are we there yet-Parallel Report to Ireland's Third and Fourth Combined Report under the UN Convention on the Rights of the Child' (Dublin, 2015) 64.

In addition, policies and programmes aimed at access to services are lacking adequate coordination and monitoring mechanisms for implementation. The former Minister for Disability acknowledged that while some areas have made progress under the Progressing Disability Services Programme 'there have also been significant challenges in implementing this programme since its launch'.[487] One important challenge at the heart of this programme is the reconfiguration of an integrated model of services through CDNTs. A full cohort of these teams has not been achieved to date as each county is at a different stage in reconfiguration.

In its concluding observations the UNCRC Committee recommended the State, 'ensure that the resources used for existing health care services for children are used in a strategic and coordinated manner'.[488] More recently, the Committee expressed its concern with the reduction in Health budgets since the 2009 economic downturn.[489] A key strategic action of the Sláintecare Implementation Strategy is to move towards universal healthcare. While this is a welcome action, the implementation strategy lacks any 'new child-specific measures to increase access to primary care'.[490] The extension of the medical card scheme to all children in receipt of Domiciliary Care Allowance (DCA) is a positive step in realising the rights of children with disabilities to access primary care. However, the high number of applications for Domiciliary Care Allowance that are refused every year and subsequently allowed on appeal is an issue.[491] To date there is no evidence that resource allocation has improved in a strategic manner to support access to services for the healthcare needs of children with disabilities.

Access to CAMHS

Access to early intervention provides better outcomes for children at risk of mental distress.[492] Demand for mental health services continues to exceed availability at all levels and many gaps remain in both the primary care and specialised CAMHS. There are significant staff shortages within CAMHS as well as delays in filling allocated posts and a lack of adequate training and development of staff.[493] In addition, Mental Health Reform[494] have expressed their concern about waiting lists for CAMHS. As noted above, waiting lists for Child and Adolescent Mental Health Services (CAMHS) remain high, with 2,300 children waiting for an appointment at end of December 2019.[495] Given the important developmental stages that children and young people go through, it was argued that 'this is a crucial time in their personal, emotional and psychological

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[487] Health Service Executive and Mary Immaculate College, Limerick, *Foreword by Minister Finian McGrath TD, Minister of State with Special Responsibility for Disabilities in Working Together to Support Children & Young People with a Disability and their Families Inaugural Conference Report* (Dublin, 2018) 1.

[488] UN Committee on the Rights of the Child, Concluding Observations on the Second Periodic Report Ireland 2006 (CRC/C/IRL/CO/2) para. 45.

[489] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4), para 18.

[490] Children's Rights Alliance, 'Report Card 2019' (Dublin, 2019) 53-54.

[491] Children's Rights Alliance, 'Report Card 2017' (Dublin, 2017) 111-112; Children's Rights Alliance, 'Report Card 2019' (Dublin, 2019) 57.

[492] Health Service Executive, *A Vision for Change, Report of the Expert Group on Mental Health Policy* (Dublin, 2006) 86.

[493] Ombudsman for Children's Office, *Annual Report 2018* (Dublin, 2019) 69; Children's Mental Health Coalition, 'Meeting the Mental Health Support Needs of Children and Adolescents' (Dublin, 2015) 10-11.

[494] Mental Health Reform 'Mental Health Reform continue to be seriously concerned about the waiting for CAMHS' (Mental Health Reform, 24 August 2019) <https://www.mentalhealthreform.ie/news/mental-health-reform-continue-to-be-seriously-concerned-about-the-waiting-for-camhs/> accessed 27 May 2020.

[495] Dáil Debate 5 March 2020, vol 992, col 882.

development which is impacted by the lack of services available to them'.[496]

In 2015, the HSE implemented a 'very intensive waiting list initiative' to address waiting lists for CAMHS. In 2019, there was a decrease of only 3.9% in the number of children and young people waiting to access specialist mental health services, despite the implementation of the waiting list initiative'.[497] In addition to over '7,000 children and young people are also waiting for primary care psychology services'.[498] Mental Health Reform recommended that the Government must take action, particularly through adequate investment in Budget 2020, to address the crisis in CAMHS so that all children and young people can get the mental health care they need, when they need it.[499]

In 2016, the UN Committee also expressed its concern about access to mental health treatment in Ireland, highlighting the inadequate availability of age-appropriate mental health units, long waiting lists to access mental health supports and the lack of out-of-hours services.[500] The Committee called on the State to improve its mental healthcare services for children and adolescents, particularly in the areas of 'inpatient treatment, out-of-hours facilities and facilities for treating eating disorders'.[501]

Lack of effective mental health legislation

While Irish mental health law has been recently reformed in the MHA 2001, literature supports the fact that children's rights are not adequately protected under it.[502] The enactment of the MHA 2001 pre-dated the drafting of the UNCRPD. The UNCRPD is driving legal reforms in many EU countries[503] and Irish law and policy should be feeding into the process of change, by helping to narrow the gap between the guarantees of international law and the lack of children's rights in national mental health law. While Government is currently developing a Mental Health Amendment Bill which may address some of these gaps, following the Report of the Expert Group on the Mental Health Act 2001,[504] it is unclear whether the Bill will fully realise all the human rights of children in respect of mental health treatment as the Heads of Bill have not been published at the time of writing.

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[496] Mental Health Reform 'Mental Health Reform continue to be seriously concerned about the waiting for CAMHS' (Mental Health Reform, 24 August 2019) <https://www.mentalhealthreform.ie/news/mental-health-reform-continue-to-be-seriously-concerned-about-the-waiting-for-camhs/> accessed 27 May 2020.

[497] ibid.

[498] ibid.

[499] ibid.

[500] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4) para 53(b).

[501] ibid.

[502] Ursula Kilkelly, *Children's Rights in Ireland Law, Policy and Practice* (Tottel Publishing Ltd 2008) 435; Mental Health Commission, *Code of Practice on the Admission of Children under the Mental Health Act 2001* (Dublin, 2006); Law Reform Commission, *Report on Children and the Law: Medical Treatment* (LRC 103 - 2011); Geoffrey Shannon, *Annual Report of the Special Rapporteur on Child Protection* (Dublin, 2010) 51; Children's Mental Health Coalition, 'Submission to the Department of Health on the Review of the Mental Health Act 2001' (Dublin, 2011).

[503] Particularly in the area of legal capacity see European Union Agency for Fundamental Rights, 'Legal Capacity of Persons with Intellectual Disability and Persons with Mental Health Problems' (Luxembourg, 2013).

[504] Department of Health, *Report of the Expert Group Review of the Mental Health Act 2001* (Dublin, 2015).

Right to consent to treatment and respect for evolving capacity

Consent to mental health treatment is covered under Part 4 of the MHA 2001. First, it is important to note that while a child's admission status—voluntary or involuntary—will determine what rights they are entitled to under the MHA 2001, this status has no effect on the child's right to consent to treatment, as this right is non-existent for all those under 18 years, irrespective of their status.[505] This lack of provision for the right to consent, leading to a lack of respect for the evolving capacity of the child and their right to participate in decision-making, is worrying.[506] It effectively permits the government to circumvent its international obligations around developing pathways to participation for children to give informed consent in mental health care. The definition in the MHA 2001 of a child as a person under the age of 18 has given rise to some difficulties, particularly in the context of the distinction between a young person's legal capacity to consent in general health care versus mental health care.[507]

Irish law and policy apply differently to children when they are ill enough to require hospital treatment in either general health care or mental health care. It is accepted that a young person of 16 or 17 years has the legal capacity to consent to treatment in general health care; this is not the case when the same young person requires in-patient mental health care. The National Consent Policy advises that if a 16 or 17-year old requires outpatient CAMHS, they have the same right to consent to treatment as other young people their age according to s.23 of the Non-Fatal Offences against the Person Act 1997.

Children who require in-patient CAMHS care and treatment will be treated differently than those who require outpatient CAMHS. This is a discriminatory approach in law and the National Consent Policy solely based on status of psycho-social disability; as it states that where a young person of 16 or 17 years has been admitted under s.25 of the MHA 2001 and requires treatment unrelated to their mental health, the general principle of consent will apply. . However, the Programme for Government does include a commitment to "Complete the update of the 2001 Mental Health Act, including amendments to allow young people, aged 16–17 years old, the right to consent to treatment for their mental health."[508] Until the Mental Health Amendment Bill is published, it will be difficult to assess whether this commitment has been fully met.

As noted above health professionals should provide 'care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care'.[509]

Arguably, the impediment to self-determination in Irish legislation is contrary to the principles in s.4 of the MHA 2001. It is difficult to see how the principles of respect for

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[505] Catríona Moloney, 'Time For Change in the Mental Health Act 2001: The law must recognise children's capacities to consent to and refuse medical treatment' (2017) 23(1) Medico-Legal Journal of Ireland 8.

[506] ibid.

[507] Inconsistency identified between the MHA 2001 and the Non-Fatal Offences against the Person Act 1997. In the 1997 Act, legal personhood is given to those over 16 years to consent to medical treatments; in contrast, the MHA 2001 sets the age of consent at 18 years.

[508] Government of Ireland, Programme for Government, 'Our Shared Future' (Dublin, 2020) 54.

[509] UNCRPD, art 25(d).

dignity, bodily integrity and autonomy apply to children when their right to consent to medical treatment is not present in the current MHA 2001. However, the government have proposed reform of the MHA 2001, which promises that the right to autonomy and self-determination will be guiding principles for the new children's section of the MHA 2001.[510] In the recent Programme for Government, a commitment was made to 'complete the update of the 2001 Mental Health Act, including amendments to allow young people, aged 16–17, the right to consent to treatment for their mental health.' [511] This will align a young person's right to legal capacity in general and mental healthcare. Unfortunately, there is no explicit commitment to a right to refuse treatment. While this is similar to the law on the right to consent in general healthcare, it is unfortunate as a decision to refuse treatment is likely to be disproportionately disregarded due to discrimination based on status in mental health sector.

As a result of the reports reviewing the MHA 2001, an amendment to section 4 was introduced by the Mental Health Amendment Act 2018 (MHA 2018). The MHA 2018 provides for a new standalone section in the 2001 Act relating to children, a reform that has been widely sought for many years. However, the new guiding principles introduced by 2018 Act are the only element in this standalone section to date.[512] Section s4A (2) of the 2018 Act provides that due regard must be given to the guiding principles in applications for admission, in decisions for care and treatment, and in the decision of the Court authorising the detention of the child. The guiding principles include:

a. for every child to have access to health services that have as the aim of those services, the delivery of the highest attainable standard of child mental health,

b. in the case of a child who is capable of forming his or her own views, to consult, where practicable, the child at each stage of diagnosis and treatment and give due weight to —

    i. his or her views, and
    ii. his or her will or preferences,

having regard to the age and maturity of that child,

c. in so far as is practicable, to provide care and treatment —

    i. in an age-appropriate environment, and
    ii. in close proximity to the child ' s home or family, as appropriate,

d. for the child to receive the least intrusive treatment possible in the least restrictive environment practicable, and

e. to respect the right of the child to dignity, bodily integrity, privacy and autonomy.[513]

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[510] Department of Health, *Report of the Expert Group Review of the Mental Health Act 2001* (Dublin, 2015).

[511] Government of Ireland, Programme for Government, 'Our Shared Future' (Dublin, 2020) 54.

[512] The government are currently working on a draft Mental Health Amendment Bill to reform the MHA 2001 and give effect to recommendations of an Expert Group Review on mental health legislation, see Office of the Government Chief Whip, Legislation Programme: Autumn Session (2020).

[513] Mental Health Act 2018, s4A(2).

If this change in law is implemented, it has great potential to shift attitudes and remove the barriers impeding children's participation in decision-making. Unfortunately, the 2018 Act has not yet commenced and therefore section 4 of the 2001 Act remains in force. The reality under 2001 Act is that children admitted voluntarily or involuntarily are subject to automatic authorisation of forced treatment if deemed necessary.

Children are in a very vulnerable position when they are admitted for treatment to an inpatient approved centre, they lack the power to exercise their own legal rights and the law provides that adults make decisions on their behalf. In addition, the Irish courts' interpretation of the principles and provisions in the MHA 2001 appears to be overly paternalistic. This goes against the rights-based approach intended for the MHA 2001 and fails to ensure its compliance with human rights standards in international and regional law. To ensure better outcomes for children and young people who require inpatient mental health care and treatment, it is vital that law and policy provide appropriate safeguards that respect, protect and fulfil their rights.

In order to remove these barriers there is an urgent requirement for the State to introduce a child rights based system in mental health law and policy.

Further support for the need to have legislative recognition of the right to consent for children with mental health problems is provided by the Committee on the Rights of the Child in its recent concluding observations on Ireland's periodic report, which recommends that Ireland '[e]nact legislation that explicitly and comprehensively provides for children's consent to and refusal of medical treatment, and ensure that this legislation should be in line with the objectives of the Convention and encompass clear recognition of children's evolving capacities'.[514]

Collaboration and coordination of services between primary care, disability and mental health

The Disability Federation of Ireland identified that the HSE divisions between mental health, disability, acute care, and primary care do not support coordinated implementation at local levels. [515] It is also noted in the CAMHS Standard Operating Procedures (2019) that prior to joint or shared care staff must comply with a number of national laws, polices and protocols in order to share information and communicate with other services.[516] This creates a bureaucratic barrier to seamless service delivery and thus a barrier to ensure the realisation of the right to health for children.

Lack of access to effective remedies

The UNCRC Committee note that children face barriers to pursuing remedies for breaches of their rights, and that this invokes a special responsibility on States to ensure there are effective child appropriate procedures available to children and their

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[514] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4) para.54(a).

[515] Disability Federation of Ireland, 'Statement to the Joint Committee on Health' (25 May 2017) <https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/joint_committee_on_health/submissions/2017/2017-05-25_opening-statement-disability-federation-of-ireland_en.pdf> accessed 20 October 2020.

[516] Health Service Executive, *Child and Adolescent Mental Health Services Operational Guidelines* (2019) 24.

representatives.[517] In the context of the right to health, children with disabilities have access to a number of existing complaints mechanisms – including the HSE's 'Your Service, Your Say' and of course the Ombudsman for Children's Office, where the complaint relates to a public body.

However, information on how to access the HSE's complaints procedures are not available in child-friendly formats or in accessible formats for children with disabilities (e.g. Easy Read, Large Print, Braille or Irish Sign Language).[518] For most issues concerning their right to health, children with disabilities will be reliant on their parents to pursue remedies on their behalf, but these options are also limited. For example, the Disability Act 2005 does not provide a remedy for the circumstances in which adequate resources are not made available to meet a child's needs as determined under the Act's provisions. Further, the National Advocacy Service, which supports adults with disabilities to seek remedies, including where their right to health has been infringed, is not currently available for children with disabilities.[519]

8.2.3 Measures to overcome identified barriers

Legislative measures

Disability Act 2005

The UNCRC Committee has recommended that the State enacts all-inclusive legislation addressing the health needs of children.[520] To date no such legislation has been introduced in Ireland.[521] A complete review of the Disability Act 2005 is recommended as it no longer aligns with current national policy,[522] or with current international human rights, particularly under the UNCRPD.

Amendments to the 2005 Act should explicitly provide for equal access to affordable, accessible and quality health services, including mental health services.[523] This would require amendments to the definition of disability which captures the broad conceptualisation of disability found under article 1 UNCRPD and builds on the social model of disability to provide a more comprehensive solution to the barriers faced by children with disabilities.[524] In addition, recognition in law that denial of reasonable accommodation to access disability services is disability based discrimination. There must be an amendment to section 7 of the Act, which ensures assessments of need and access to services are based on health needs of the child rather than diagnosis.

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[517] UN Committee on the Rights of the Child, General comment No. 12 (2009): The right of the child to be heard (CRC/C/GC/12).

[518] Health Service Executive, HSE Complaints and Feedback (Health Service Executive, 2020) <https://www2.hse.ie/services/hse-complaints-and-feedback/your-service-your-say.html> accessed 15 October 2020.

[519] National Advocacy Service, 'About us' (2020) <https://advocacy.ie/about-us/> accessed 15 October 2020.

[520] UN Committee on the Rights of the Child, Concluding Observations on the Second Periodic Report Ireland 2006 (CRC/C/IRL/CO/2) para. 45.

[521] Ombudsman for Children's Office, *Report of the Ombudsman for Children to the UN Committee on the Rights of the Children on the occasion of the examination of Ireland's consolidated Third and Fourth Report to the Committee* (Dublin, 2015) 35.

[522] Ombudsman for Children's Office, *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (Dublin, 2020) 14-15.

[523] Office of the High Commissioner for Human Rights, 'Bridging the Gap: Human Rights indicators - Article 25' (Geneva, 2019).

[524] See concept of disability in Section 2 above.

Legislative measures are also required to strengthen coordination between agencies on cross sectoral issues for children with disabilities, such as HSE CAMHS and disability services. An amendment to the Disability Act or Mental Health Act could also provide for communication and sharing of information to better meet the needs of children requiring access to both services. This has been recommended with respect other legislation as part of the review of the Child Care Act 1991.[525]

Mental Health Act 2001

Under current mental health law children have no recognised legislative rights protection regarding consent to or refusal of admission and treatment. The MHA 2001 must be amended to provide for free and informed consent and the right to refuse treatment notwithstanding legal capacity status.[526] In addition, health information and information on the right to consent must be made available and accessible. An amendment to include a right to information is necessary to achieve this.

Administrative and other measures

Disability services

There are numerous policies and programmes promising to create an equitable and accessible healthcare system for children with disabilities, including children with mental health difficulties. However, these national policies and programmes are fragmented and ineffective in their approach to achieving the principles of equity and accessibility. This is due to various reasons, such as; lack of measurable targets, deliverables and timeframes to achieve key actions;[527] lack of action or implementation plans and monitoring mechanisms. New administrative guidance will be required based on the legislative measures suggested above, if implemented.

A review of existing policies and programmes is suggested with the objective of developing a comprehensive national child health strategy aimed at implementing equal access to affordable, accessible and quality health services, including mental health services, for all children, including those with disabilities. The new strategy should aim to fully implement the Progressing Disability Services Programme (2011). It must be linked to action and implementation plans to ensure the realisation of the right to health for children with disabilities. The comprehensive strategy can be elaborated on through focused action plans in relevant areas. These plans must set out specific goals, targeted implementation measures and the allocation of financial and human resources.[528]

The new strategy should consider incorporating a reviewed version of the Outcomes Focused Performance Management and Accountability Framework 2013.[529] This

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[525] See Participation in Section 5: Overarching & cross cutting issues.

[526] Office of the High Commissioner for Human Rights, 'Bridging the Gap: Human Rights indicators - Article 25' (Geneva, 2019).

[527] The National Disability Inclusion Strategy 2017 - 2021 is an example of this.

[528] UN Committee on the Rights of the Child, General Comment No. 5 (2003): General measures of implementation of the Convention on the Rights of the Child (CRC/GC/2003/5).

[529] Health Service Executive, *Outcomes for Children and their Families-Report on an Outcomes-Focused Performance Management and Accountability Framework for Early Intervention and School Age Disability Network Teams* (Dublin, 2013). This framework was based on extensive consultation with children, young people, their families and other key stakeholders.

framework set out goals and indicators aimed at measuring success in meeting best possible health outcomes for the child and young person with a disability. Currently, it lacks a sustainable process for realising this right,[530] although it does provide a section on general measurement of outcomes which lists what a process might look like. The framework would benefit from a detailed breakdown of specific measures to be taken to achieve the health outcome statement.

A monitoring body should also be established with responsibility to publish reports highlighting data on progress in achieving of any indicator and outcomes framework. The framework should also provide for a review mechanism to maintain momentum for implementation and data collection. It is essential that the measures support the move towards the goal of access to universal health coverage.[531]

CAMHS

The HSE should introduce a Protocol on free and informed consent, offering information to children and young people and guidance to healthcare professionals working with them. Guidance should inform staff on issues such as respect for the evolving capacity of children and young people in decision-making.

Consideration should be given to incorporating a child-friendly healthcare system, with administrative guidance on processes developed that are accessible, age appropriate, adapted to and focused on the needs and rights of the child, including the right to complaints and appeals, and to participate in and understand any proceedings they are involved in. This should apply to Assessment of Need processes and admission and treatment procedures for inpatient CAMHS.

Allocation of resources

There is no evident budget or specific allocation of resources for health services for children with disabilities. To ensure the realisation of the rights of children with disabilities it is important that the Government prepare estimates for expenditure in healthcare for children with disabilities. The proportion of budgets allocated to children with disabilities should be clearly identified.[532] The State must take measures to assess the budget needs of children with disabilities, including setting up specific budgetary lines for use in the healthcare sector. Children must be made visible in budgets.[533] A tracking system for the allocation and use of resources for children with disabilities has been recommended by the UNCRC Committee.[534]

Additional resources are also required to ensure adequate staff can accommodate children with disabilities based on need and reduce waiting lists. The proportion of the

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[530] UN Committee on the Rights of the Child, General Comment No. 5 (2003): General measures of implementation of the Convention on the Rights of the Child (CRC/GC/2003/5) para 32.

[531] Office of the High Commissioner for Human Rights, 'Bridging the Gap: Human Rights indicators - Article 25' (Geneva, 2019).

[532] See Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People 2014- 2020* (Dublin, 2014) 31. 43; Office of the High Commissioner for Human Rights, 'Towards better investment in the rights of the child' (A/HRC/28/33) para 35.

[533] UN Committee on the Rights of the Child, General Comment No. 5 (2003): General measures of implementation of the Convention on the Rights of the Child (CRC/GC/2003/5) para 51.

[534] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4), para 16.

health budget designated to mental health which is allocated to community-based services and support (as opposed to budget allocated to psychiatric hospitals and beds) needs to be significantly increased in order to address this gap in support for children and young people with psychosocial disabilities.

Remedies

Children require support to access complaints and appeals systems to exercise their rights to health, including a right to advocacy and legal representation. Any complaints and appeals systems introduced should also be fully accessible to children with disabilities, and provide information and support in accessible formats including Irish Sign Language, Braille, Easy to Read and Large Print. Children subject to the Mental Health Act 2001 also require access to supports and a right to advocacy to support decision making around treatment and admission.

Consultation and monitoring

Consultation processes need to be undertaken to ensure the active involvement of children with disabilities, including through their representative organizations, in the design, implementation and monitoring of laws, regulations, policies and programmes, related to health.[535] This is an important measure to ensure the realisation of the rights of children with disabilities and to ensure they are made visible in matters affecting them. NDIS is an example where the monitoring implementation group comprises of no individuals or organisations whose specific remit is to represent children with disabilities.

Training and Awareness-Raising

Awareness raising campaigns on the human rights of children with disabilities as expressed in the CRC and CRPD need to be developed alongside activities directed to children with disabilities and their families concerning health information, programmes and services for children with disabilities.[536] Further, mandatory training should be made available for all healthcare professionals on key principles of right to health for children with disabilities. This should include opportunities for continuous professional development as well as changes to the curricula in universities for student healthcare professionals.[537] In keeping with the principles of the CRC and CRPD, children with disabilities and their representative organisations should be involved in designing and delivering these training and awareness-raising programmes.

Data collection and analysis

It is essential not merely to establish effective systems for data collection on the health status and outcomes of children with disabilities, but to ensure that the data collected are evaluated and used to assess progress in implementation, to identify

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[535] Office of the High Commissioner for Human Rights, 'Bridging the Gap: Human Rights indicators - Article 25' (Geneva, 2019).

[536] ibid.

[537] ibid.

problems.[538] For example, the HSE needs urgently to recommence the publication of its annual reports for CAMHS (which have not been published since 2013).[539] While some information on the health of children (including children with disabilities) is available in Growing Up in Ireland, reports have not yet been published from this study to document how access to general or specialist health services (including mental health) has been secured for the cohorts under study.[540]

8.3 Adequate standard of living

The right to an adequate standard of living requires, at a minimum, that everyone shall enjoy the necessary subsistence rights: adequate food and nutrition, clothing, housing and the necessary conditions of care when required. In purely material terms, an adequate standard of living implies living above the poverty line of the society concerned.

The right to an adequate standard of living is included in several human rights treaties. Article 27 UNCRC provides that 'States Parties recognise the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development'. In 2016, the UNCRC Committee expressed its deep concern at the 'significant increase in the number of children living in consistent poverty' and in particular referred to single-parent households.[541] While this acknowledgment did not specifically reference children with disabilities, global research demonstrates that people with disabilities, including children, are at a consistently higher risk of poverty than their non-disabled peers.[542]

Article 28 of the UNCRPD provides that 'States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.' Further, 'States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability and shall take appropriate steps to safeguard and promote the realization of this right'.[543]

While literature generally considers the economic costs of disability for adults and their families, more recent research has also considered some of these issues for children with disabilities.[544] In particular, research conducted by Cullinan and Roddy presented a socioeconomic profile of childhood disability in an Irish context. Using data from the Growing Up in Ireland survey, it considered the association between a range of socioeconomic measures and the disability status of nine-year-old children in Ireland.

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[538] UN Committee on the Rights of the Child, General Comment No. 5 (2003): General measures of implementation of the Convention on the Rights of the Child (CRC/GC/2003/5) para 48.

[539] Growing Up in Ireland, 'Key Findings, Infant Cohort at 7/8 years: Health and Development (No 2)' (Dublin, 2017) 8.

[540] Growing Up In Ireland, 'Key Finding, Cohort '08 at 9 years old: Health and Physical development (No 3)' (Dublin, 2018).

[541] UN Committee on the Rights of the Child, Concluding observations on the combined third and fourth periodic reports of Ireland 2016 (CRC/C/IRL/CO/3-4) para 59.

[542] World Health Organisation, 'World Report on Disability' (Malta, 2011) 39.

[543] UNCRPD, art 28.

[544] John Cullinan and Aine Roddy 'A socioeconomic profile of childhood disability' in John Cullinan, Seán Lyons and Brian Nolan (eds), *The Economics of Disability* (Manchester University Press 2015).

The findings suggest that the primary carer of a child with a disability is considerably less likely to be employed and more likely to turn down work opportunities, when compared to a primary carer of a child without a disability. If a child's disability is more complex the differences between parents are found to be more pronounced. Similar patterns were also found in relation to parental education and social class. Parents of a child with a disability are less likely to be educated at third level and more likely to be in the lowest social class. As a result, these households also tend to have lower incomes and much greater difficulty in meeting necessary subsistence standards, such as adequate food, nutrition and clothing. The socioeconomic measures examined in the research indicate that the presence of a child with a disability in a household was strongly correlated with worse outcomes. This is similar to findings in the United Kingdom which show that families with a disabled child are included among the groups disproportionately more likely to be in poverty and affected by socio-economic disadvantage.[545] In considering this research, it is important to acknowledge the intangible costs of childhood disability to the child, their family and society.[546]

8.3.1 Current Irish Context: Overview of law and policy

The right to an adequate standard of living is not explicitly protected in the Irish Constitution. According to O'Gorman, there is a need to place the right to health and to an adequate standard of living into the Irish Constitution.[547]

Since 1997 Ireland has developed national anti-poverty strategies to provide a strategic framework in which to tackle poverty and social exclusion. Over the years a range of national sectoral strategies have been developed across government which include social inclusion as a core objective. The Department of Employment Affairs and Social Protection (DEASP) has overall responsibility for the development of a whole-of-government policy focusing on reducing poverty and improving social inclusion.[548]

In January 2020, the DEASP published the Roadmap for Social Inclusion 2020–2025 Ambition, Goals and Commitments. This whole-of-government strategy will build on the work of its predecessors with the aim of reducing the number of people in consistent poverty in Ireland and increasing social inclusion for those who are most disadvantaged.[549] However, the Roadmap does include a Government commitment to reduce the at risk of poverty rate for people with disabilities from 36.9% first to 28.7% (by 2025) and then to 22.7% (by 2030). The Roadmap also makes a commitment on behalf of the Department of Employment Affairs and Social Protection and the Department of Public Expenditure and Reform to commission a study on the cost of disability and publish a final report with recommendations by Q2 2020. In June 2019, it was announced that Indecon International had successfully won a tender competition

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[545] Equality and Human Rights Commission, 'Disability rights in the UK: UK Independent Mechanism updated submission to the CRPD Committee' (London, 2017) 46.

[546] John Cullinan, 'The Economic Costs of Disability for Families' (Frontline, 16 February 2015) <https://frontline-ireland.com/economic-costs-disability-families/> accessed 7 May 2020.

[547] Colm O'Gorman 'New RED C Poll for Amnesty International shows strong support for Constitutional protection of additional human rights' (16 February 2014) <https://www.amnesty.ie/constitutional-protection-economic-social-cultural-rights/> accessed 5 May 2020.

[548] Department of Employment Affairs and Social Protection, 'Social Inclusion Division' (14 January 2020) <https://www.gov.ie/en/organisation-information/be955a-social-inclusion-division/> accessed 6 May 2020.

[549] Department of Employment Affairs and Social Protection, *Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals and Commitments* (Dublin, 2020) 2.

to develop this research,[550] but no report has yet been made publicly available at the time of writing. Indecon had also completed a previous study of the cost of disability for the National Disability Authority in 2011.[551] The Roadmap's actions on child poverty do not specifically address children with disabilities but do include a commitment to reduce the at risk of poverty rate for children from 23.9% to 16% by 2030.

The right to an adequate standard of living also features in the National Policy Framework for Children and Young People where the government is committed to ensure economic security and opportunity under National Outcome 4.[552] The Government recognised that every child should grow up in a family with access to sufficient resources, supports and services to nurture and care for the child, and to foster the child's development and full and equal participation in society.[553]

According to Eurostat data Ireland has one of the best poverty reduction effects from social transfers of all EU Member States.[554] However, despite the positive effect of social transfers on reducing the poverty gap of children, Ireland's child poverty outcomes are not as good relative to other European countries.[555] According to the European Commission,[556] the most effective strategies in addressing child poverty are those underpinned by policies that focus on prevention and improving the wellbeing of all children and young people, while giving targeted support to children and young people with additional needs.

Research has recognised that the most effective strategy for ending child poverty, including poverty of children with disabilities, is to provide adequate income support for parents.[557] The only social welfare payment in Ireland available to support parents of children with disabilities specifically is the Domiciliary Care Allowance. This non-means tested allowance is made to parents of children with severe disabilities who require ongoing care and attention, substantially over and above the care and attention usually required by a child of the same age. As noted above,[558] the high number of applications for Domiciliary Care Allowance that are refused every year and subsequently allowed on appeal is a cause for concern in ensuring an adequate standard of living for children with disabilities.

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[550] Department of Employment Affairs and Social Protection, 'Press Release: Indecon International Consultants commissioned to carry-out Cost of Disability Research' (9 June 2019) <https://www.gov.ie/en/press-release/fd13cd-indecon-international-consultants-commissioned-to-carry-out-cost-of-/> accessed 16 October 2020.

[551] Indecon International Economic Consultants, 'Cost of Disability Research Project' (2004) NDA <http://nda.ie/File-upload/Indecon-Report-on-the-Cost-of-Disability.pdf> accessed 16 October 2020.

[552] Department of Children and Youth Affairs, *Better Outcomes Brighter Futures- the National Policy Framework for Children and Young People 2014-2020* (Dublin, 2014) 89-94.

[553] ibid 89.

[554] Eurostat, 'People at Risk of Poverty by level of activity limitation, sex and age' (hlth_dpe020 – 15 October 2020) <https://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=hlth_dpe020> accessed 16 October 2020.

[555] Organization for Economic Co-operation and Development (OECD), 'Doing Better for Families' (Paris, 2011), at 90.

[556] European Commission, *Commission Recommendation. Investing in Children: Breaking the cycle of Disadvantage* (Brussels, 2013).

[557] John Cullinan and Aine Roddy 'A socioeconomic profile of childhood disability' in John Cullinan, Seán Lyons and Brian Nolan (eds), *The Economics of Disability* (Manchester University Press 2015).

[558] Children's Rights Alliance, 'Report Card 2017' (Dublin, 2017) 111-112; Children's Rights Alliance, 'Report Card 2019' (Dublin, 2019) 57.

8.3.2 Key barriers to the realisation of rights

No legal provisions to underpin right to adequate standard of living

As noted above, there are explicit justiciable Constitutional or legislative provisions on the right to an adequate standard of living which are inclusive of children with disabilities. Social welfare legislation does not extend to the recognition of a right to an adequate standard of living and the non-directive principles of social policy in the Constitution are not justiciable. This leaves children with disabilities without legal protection for this human right.

Invisibility of children with disabilities within anti-poverty strategies

The Roadmap for Social Inclusion 2020–2025 Ambition, Goals and Commitments, does not include a single reference to children with disabilities in the actions set out by Government. As noted above, no specific targets for children with disabilities appear in either the sections on children or on people with disabilities. Many anti-poverty measures are focused on getting more people into employment to reduce income inequality and improve standards of living. While this is important, many parents of children with disabilities are not in a position to take up full time employment due to caring responsibilities. Further, while access to employment is a key target for adults with disabilities, it is not appropriate for children with disabilities, and therefore, children with disabilities are falling through the gaps of existing anti-poverty strategies.

Lack of specific income-supports targeted at children with disabilities

With the exception of Domiciliary Care Allowance, there are no social welfare payments which explicitly target children with disabilities. While increases in the amount paid in Child Benefit are available to twins, triplets and other multiple births, there are no increases available for children with disabilities. There is at present no cost of disability payment which could be targeted to meet the additional costs incurred by households which include children with disabilities.

8.3.3 Measures to overcome barriers identified

Legislative Measures

A right to an adequate standard of living (which is inclusive of children with disabilities) should be codified in law. This could be done in a number of ways, including through Constitutional amendment, or by introducing new stand-alone legislation. In any legal provision to address this right, it will be important to include specific reference to children with disabilities, and related measures to support them (for example, through increasing existing social welfare payments and/or introducing new payments to families which include children with disabilities as discussed under the Administrative Measures below). Commitments to end child poverty could also be codified in legislation, rather than relegating such commitments to the realm of social policy, where they remain non-justiciable. [559]

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[559] The UK have enacted the Child Poverty Act 2010, which puts in legislation a commitment to eradicate child poverty.

Administrative and Other Measures

Provide additional social welfare supports targeted at children with disabilities

In order to address income inequalities in households which include children with disabilities, additional social welfare supports are required. This could be achieved in a number of ways, including by increasing the rate of existing payments such as the Domiciliary Care Allowance, and adding new payments, such as the cost of disability allowance. Since the Domiciliary Care Allowance only applies to children with severe disabilities, an introduction to child benefit in respect of all children with disabilities would also address income inequalities in households which include children with disabilities.

Include specific targets for children with disabilities in anti-poverty strategies

In order to address the invisibility of children with disabilities in anti-poverty strategies, specific targets for this group need to be added to these initiatives, including the Roadmap for Social Inclusion 2020 – 2025. Specific measures to ensure the right to an adequate standard of living for children should include specific reference and measures for children with disabilities, and strategies targeted at people with disabilities must include discrete targets for adults and children with disabilities.

Data collection and analysis

An understanding of all of the causes of poverty, deprivation and social exclusion among the parents of children with disabilities, and children with disabilities themselves, is needed. DEASP should collect data on the latter issues with the active involvement of children with disabilities and their families, and use this to formulate an action plan specific to their needs to ensure better standards of living across the lifecycle. Transitions from childhood to adulthood should be a key issue in the data collection. In addition, consideration should be given to approaches that involve increasing income and reducing costs for families.[560]

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[560] Department of Employment Affairs and Social Protection, *Poverty and Disability; A public-friendly guide to economic inequality and the cost of disability* (Dublin, November 2017) 6.

9. Cluster 4 – Justice/Redress & Safeguards

9.1 Liberty and Security

Persons with disabilities are at heightened risk of unique forms of deprivation of liberty – including detention in psychiatric hospitals, nursing homes and other institutional settings as well as forced treatment.[561] Although recognised as needing urgent attention by different stakeholders, limited data is available on the wide range of disability specific forms of deprivation of liberty, including those affecting children with disabilities.[562]

Article 14 of the UNCRPD, states that States Parties shall ensure that persons with disabilities 'are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty'. This applies equally to persons with mental disabilities or psychosocial disabilities.[563] Further, States Parties shall ensure that 'if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation'.[564]

Article 37 of the UNCRC also guarantees a child's right to liberty and includes similar provisions prohibiting unlawful or arbitrary detention It additionally requires States Parties to ensure a child is treated with humanity, inherent dignity, and 'in a manner which takes into account the needs of persons of his or her age'.[565] Any arrest, detention or imprisonment of a child should be used 'only as a measure of last resort and for the shortest appropriate period of time' and shall be separate to adults unless that is not in a child's best interests.

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[561] Eilionóir Flynn, Mónica Pinilla-Rocancio and María Gómez-Carrillo, 'Report on disability-specific forms of deprivation of liberty' (April 2019) 10 <https://www.nuigalway.ie/media/centrefordisabilitylawandpolicy/files/DoL-Report-Final.pdf> accessed 11 May 2020.

[562] ibid.

[563] United Nation Human Rights Office of the High Commissioner, *Statement on article 14 of the Convention on the Rights of Persons with Disabilities* (Geneva, 2014) <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15183> accessed 10 May 2020.

[564] UNCRPD, art 14.

[565] UNCRC, art 37.

9.1.1 Current Irish Context

9.1.1.1 Profile of children with disabilities

According to Tusla, there were 6,029 children in State care at the end of 2018.[566] 365 (6%) children were in mainstream residential care, of which 126 (34.5%) were in Tusla placements and 239 (65.5%) were in residential centres run by private and voluntary-body providers.[567] There were 14 children in special care units.[568] A further 94 children were in other care facilities including supported lodgings, at home under a care order, in a detention school/centre, other residential centre (e.g., disability unit or drug and alcohol rehabilitation centre).[569] The 2019 HIQA report does not provide similar data breaking down the proportion of children with disabilities in residential services under its remit.[570]

The 10th national psychiatric census found that there were 83 children resident in either adult psychiatric units or specialised child and adolescent units on the 31 March 2019.[571] Of those 78 children were in child and adolescent units and 5 children were placed in adult units.[572] Of the under 18s resident in psychiatric units or hospitals the report documents that in excess of two-thirds (69%) of those were female. It further recounts that 42% per cent were aged 17 years, 17% were aged 16 years, just over 20% were aged 15 years and a similar proportion were aged 14 years or younger.[573] The report noted an increase in the number of under 18s in hospitals and units, from 43 in 2010 to 83 in 2019.[574] This is attributed in part, to the increased in-patient capacity over the years and to the growth in demand for places.[575]

In its annual report, Oberstown's Children Detention Campus reported that of the 75 children detained on the campus in the first quarter of 2019, 41% had mental health needs identified, 8% had a physical health concern and 23% had a diagnosis of learning disability.[576]

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[566] Health Information and Quality Authority, *Annual overview report on the inspection and regulation of children's services – 2018* (June 2019) 15 <https://www.hiqa.ie/sites/default/files/2019-06/HIQA-Childrens-Overview-Report-2018.pdf> accessed 09 June 2020.

[567] ibid.

[568] ibid 16.

[569] ibid.

[570] Health Information and Quality Authority, *Annual overview report on the inspection and regulation of children's services – 2019* (June 2020) <https://www.hiqa.ie/sites/default/files/2020-06/2019-Childrens-Overview-report_0.pdf> accessed 09 June 2020.

[571] Antoinette Daly and Sarah Craig, 'Irish Psychiatric Units and Hospitals Census 2019 Main Findings' (Dublin: Health Research Board, 2020) 17.

[572] ibid 18.

[573] ibid 17.

[574] ibid 17.

[575] ibid.

[576] Oberstown Children Detention Campus, 'Annual Report 2019' (June 2020) 9 <https://www.oberstown.com/wp-content/uploads/_pda/2020/07/Oberstown-Annual-Report-2019.pdf?t=5f1959a00a7f0> accessed 27 August 2020.

9.1.1.2 Overview of law and policy

The right to liberty and security in Ireland is guaranteed within the Irish Constitution, which provides that no citizen shall be deprived of his personal liberty except in accordance with the law.[577] The right is further protected under article 5, Schedule 1 of the Irish Human Rights and Equality Commission Act 2014.

Criminal Law

Where children are detained by An Garda Síochána in the investigation of a criminal offence, Gardaí must respect their personal rights, dignity and any vulnerability arising from special needs or disability.[578] There is little guidance publicly available on how children with disabilities should be accommodated when detained by Gardaí or which process are in place to ensure this complies with international human rights standards. Where children are convicted of a criminal offence, they may be detained in the national children's detention campus at Oberstown. Each child's specific needs are assessed, and an individual care plan is developed when initially detained.[579] The campus' strategic plan for 2017–2020 contains no specific reference to meeting the needs of children with disabilities or mental health diagnoses.[580]

Civil Law

Children may be deprived of their liberty under the MHA 2001 for the treatment of 'mental disorders' or 'mental illness'.[581] Children may be admitted as voluntary or involuntary patients. Under the Act a child, anyone under 18 who has not been married,[582] is a voluntary patient if their parents or guardians consent to their treatment and detention in a relevant facility.[583] As voluntary patients there are no procedural safeguards for the review of their detention or treatment even though the child himself/herself has not consented. Involuntary detention orders are decided by the District Court and required for children who are in the care of the State under the Child Care Act 1991 and for children who are unlikely to receive the necessary treatment otherwise.[584]

This initial detention for 21 days may be extended for 3 months and following that for another period of a maximum of 6 months.[585] A 2011 Law Reform Commission report highlighted their belief that parental consent is used in many instances to circumvent the need to apply to the court for an involuntary detention order.[586] It noted that while the MHA retains the distinction between voluntary and involuntary treatment and detention for children in theory, it is almost non-existent in practice.[587] This is reflected by the statistics provided by the Mental Health Commission.

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[577] Constitution of Ireland, art 40.4

[578] Children Act 2001, s55.

[579] Oberstown Children Detention Campus, 'Model of Care' <https://www.oberstown.com/what-we-do/model-of-care/?cn-reloaded=1> accessed 02 February 2021.

[580] Oberstown Children Detention Campus, 'Strategy 2017 – 2020' (June 2016) <https://www.oberstown.com/wp-content/uploads/2017/12/Oberstown-Strategy-2017-2020-1.pdf> accessed 27 August 2020.

[581] Mental Health Act 2001, s2(1).

[582] ibid.

[583] Catríona Moloney, 'Mental Health Act 2001: A Child Rights Assessment of the Current Legal Framework and Its Proposed Reform—Part I' (2016) 19 Irish Journal of Family Law 28.

[584] Mental Health Act 2001, s25.

[585] ibid, s25(9) and (10).

[586] Law Reform Commission, *Children and the Law Medical Treatment* (LRC 103-2011), 120.

[587] ibid.

In their latest Annual Report for 2019,[588] the MHC reported the total number of admissions of children to approved centres was 497. This is an increase from the 408 admissions in 2018 and 439 in 2017.[589] In 2019, 32 children were admitted to approved centres under involuntary admission orders. This included 2 children admitted to adult units.[590] In addition, one child was admitted to an adult unit following a High Court Order. This leaves a total of 464 children admitted "voluntarily" with parental consent.

In an amendment to the Code of Practice Relating to the Admission of Children under the Mental Health Act 2001 the MHC committed to ensuring that no child, under the age of 18, would be admitted to an adult unit after the 1st December 2011.[591] If this occurs there is a duty on the approved centre to submit a report outlining why to the MHC.[592] However, in 2019 54 children were admitted to 15 adult units across Ireland. Media coverage of this issue continues to highlight the unacceptable number of children admitted to adults units, with one in five children being treated in facilities not created to meet their needs.[593] The literature indicates that children respond best when services are specific to their needs, and that children with mental health problems require safe environments to develop resilience to cope with mental health issues.[594] The UNCRC Committee has expressed their concern over children being admitted to adult units and recommended the prioritisation of the strengthening of inpatient CAMHS.[595]

A child between the ages of 11 and 18 years of age may also be detained for treatment to address behaviour which 'poses a real and substantial risk of harm to his or her life, health, safety, development or welfare' and does not come within the definition of a 'mental disorder' under the MHA 2001.[596] The Child Care Law Reporting Project has shown that these orders are often applied to children with psychosocial disabilities.[597] The project has also highlighted the High Court's use of its inherent jurisdiction and Wardship to place children with disabilities in treatment facilities in other jurisdictions, primarily the UK.[598] This is attributed to the limited definition of 'mental disorder' under the MHA and a lack of appropriate treatment facilities in Ireland.[599] When placed in treatment facilities in another jurisdiction the case remains under the jurisdiction of the Irish High Court however, the child also becomes subject to UK legislation regarding consent to treatment, discharge and deprivation of liberty.

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[588] Mental Health Commission, *Annual Report 2019* (Dublin, 2019) 27.

[589] ibid.

[590] ibid, 28.

[591] Mental Health Commission, *Code of Practice Relating to Admission of Children under the Mental Health Act 2001 Addendum* (Dublin, 2009) 3.

[592] ibid.

[593] Sheila Wayman, 'Inpatient psychiatric care for under-18s exposes health system flaws' *The Irish Times* (Dublin, 13 August 2020); Catherine Shanahan, 'Admitting Children to Adult Psychiatric Units 'Common' *Irish Examiner* (Dublin, 15 October 2019); Sarah Bardon, 'Fifty Children Admitted to Adult Psychiatric Units this Year' *The Irish Times* (Dublin, 10 August 2015).

[594] Health Service Executive, *A Vision for Change Report of the Expert Group on Mental Health Policy* (2006) 85; Bates et al, *Someone to Turn to Someone to Talk to* (Headstrong 2009) 23; Law Reform Commission, *Consultation Paper Children and the Law: Medical Treatment* (Stationery Office 2009) 177.

[595] UN Committee on the Rights of the Child, Concluding Observations on the Combined third and fourth Periodic Reports of Ireland 2016 (CRC/C/IRL/CO/3-4) para 54(b).

[596] Child Care (Amendment) Act 2011, s23H.

[597] Child Care Law Reporting Project, Cases <https://www.childlawproject.ie/publications/> accessed 6 April 2020.

[598] Lisa Colfer and Carol Coulter, 'High Court Oversight of Children's Complex Care Needs - Child Care Law Reporting Project' <https://www.childlawproject.ie/publications/high-court-oversight-of-childrens-complex-care-needs/> accessed 9 June 2020.

[599] ibid.

To comply with its obligations under the UNCRPD, draft Heads of Bill were published to provide for safeguards against the deprivation of liberty and procedures for the admission, detention, treatment review of any person detained in a 'relevant facility'. The results of a public consultation on these Heads of `Bill were published in July 2019.[600] However, these safeguards do not address children deprived of their liberty and there have been no further updates or progress in this regard.

9.1.2 Key barriers to the realisation of rights

Overwhelming lack of information, guidance or safeguards

There is an overwhelming lack of information, guidance or safeguards regarding children deprived of their liberty in Ireland. This is of particular concern regarding children with disabilities who, like adults with disabilities, are at an increased likelihood of being deprived of their liberty, as noted above. Children are not considered under the current proposed draft Deprivation of Liberty safeguards[601] nor are there clear guidelines for when a child may be considered deprived of their liberty and how this may be challenged. This is further reflected by the fact that children admitted to residential care facilities for persons with disabilities with the consent of their parents or under the Child Care Act are not currently recognised as deprived of their liberty. In relation to children detained under the criminal law there is also no national guidance for An Garda Síochána on the deprivation of liberty of children with disabilities nor are there specific actions identified for children with disabilities or mental health needs detained in Oberstown Children Detention Campus.

Inadequate safeguards and supports for children under the Mental Health Act 2001

Children aged 16 or 17 years old treated as voluntary patients, based on their parents' consent, under the Mental Health Act 2001 - are not entitled to a review of their admission.[602] The absence of a review procedure and the lack of a national advocacy service for people under 18 accessing mental health services may lead to children with disabilities being deprived of their liberty in a mental healthcare setting without an opportunity to challenge this decision or express their views, contrary to international human rights law and best practice.

Absence of appropriate facilities for children with psychosocial disabilities

The absence of appropriate legislative measures or treatment facilities for children with psychosocial disabilities has led to their treatment in inappropriate adult facilities. Others are treated in other jurisdictions with different legislative safeguards and reduced access to family and other supports. Notwithstanding, international standards and best practice, Ireland fails to provide a right to treatment in age-appropriate facilities for children subject to inpatient CAMHS or access to appropriate alternatives to inpatient care (community-based services).

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[600] Department of Health, *The Deprivation of Liberty Safeguard Proposals: Report on the Public Consultation* (July 2019) <https://assets.gov.ie/43856/286eb5d2ebca4b088d65cfef7b5c23a2.pdf> accessed 9 June 2020.

[601] Department of Health, *The Deprivation of Liberty Safeguard Proposals: Report on the Public Consultation* (July 2019) <https://assets.gov.ie/43856/286eb5d2ebca4b088d65cfef7b5c23a2.pdf> accessed 9 June 2020.

[602] Mental Health Reform, 'Briefing note on reform of the Mental Health Act, 2001' (13 June 2019) <https://www.mentalhealthreform.ie/news/briefing-note-on-reform-of-the-mental-health-act-2001/> accessed 2 June 2020.

9.1.3 Measures to overcome identified barriers

Legislative measures

Legislation regarding the admission of children to mental health and other facilities is urgently required to cement safeguards for the right to liberty for all children with disabilities, in particular those with psychosocial disabilities. This should recognise the evolving capacities of the child, in line with the UNCRPD and UNCRC, and the principles of free and informed consent.[603] This could take the form of amendments to existing legislation, such as the Mental Health Act, a new piece of legislation as envisaged by the Law Reform Commission in their 2011 report,[604] or may be addressed under the Bill currently being explored by the Department of Health in consultation with the Mental Health Commission and the HSE.[605]

A new piece of legislation may provide a clearer and more comprehensive mechanism and would allow specific deprivation of liberty safeguards for children. The safeguards currently outlined are proposed as amendments to the Assisted Decision – Making (Capacity) Act 2015, which only applies to those over the age of eighteen.

Justiciability of rights

Children admitted to approved centres and potentially deprived of their liberty as ‘voluntary’ patients based on their parents’ consent must have access to a mechanism to review their admission. This procedure must support children to express their views, including through the provision of an independent advocate and communication supports.

Administrative and other measures

Funding

Funding must be provided to ensure CAMHS has sufficient resources to support children with psychosocial disabilities in appropriate settings. Such funding must resource alternatives to inpatient care (community-based services) that will lead to a reduction in hospital admissions.

Training and guidance

Members of An Garda Síochána and other professionals interacting with children with disabilities who may be deprived of their liberty must be provided with human rights compliant guidance on disability supports, reasonable accommodation and safeguards. Training should also be provided, as either CPD or during initial training.

Additional guidelines and codes of practice, based on a human rights approach, must be provided on working with children who may be deprived of their liberty or when eliciting consent for treatment or detention to ensure professionals working in the field understand their responsibilities and are adequately supported to undertake their role.

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[603] Office of the High Commissioner for Human Rights, ‘Bridging the Gap: Human Rights indicators, Article 25: Illustrative Indicators on the right to health’ (Geneva, 2019).

[604] Law Reform Commission, *Children and the Law Medical Treatment* (LRC 103-2011).

[605] Dáil Debates 8 September 2020, *Vol. 996 No. 6, col 1405.*

The delivery of training or the development of guidance - this must be decided in partnership with children with disabilities or their representatives in line with General Comment 7 of the UNCRPD.

Data Collection

A programme of data collection should be instigated which collects detailed information regarding the number of children deprived of their liberty or admitted to treatment facilities, residential units or others services to understand the extent of the issues faced and act as a baseline to monitor future reform. This must include information regarding disability specific deprivations of liberty and disaggregate data on admissions/detentions based on the presence of a disability or impairment and age.

Comprehensive plans

All settings where children may be detained, such as Oberstown Detention Campus or mental health treatment facilities, should be required to outline in detail how they will support children with disabilities, uphold their human rights (including their right to express their views) and fulfil their requirements for accessibility and reasonable accommodation. While existing inspections and reviews, undertaken by HIQA or the Mental Health Commission, consider child rights compliance there is little emphasis on disability specifically and reasonable accommodations in relation to children's facilities. Therefore, any comprehensive plans drafted should be subject to regular review and updates and disability specific questions should form part of any inspection of the facility.

9.2 Access to Justice

In the absence of access to justice, people are unable to have their voice heard, exercise their rights, challenge discrimination or hold decision-makers accountable. Effective access to justice enables and empowers people to vindicate their rights and in doing so is seen as transforming fundamental rights from theory into reality.[606] Children with disabilities are guaranteed this right on an equal basis with others under article 13 of the UNCRPD and articles 12, 39 and 40 of the UNCRC.

Access to justice, under article 13 of the UNCRPD, covers both direct (the parties to a case) and indirect (witnesses etc.) participants. It has a broad scope and requires States Parties to ensure persons with disabilities equal and effective participation at all stages of the process including 'investigative and other preliminary stages'. The article applies to children with disabilities equally, with article 13(1) highlighting 'procedural and age-appropriate accommodations' as a requirement to ensure effective access. State Parties must ensure that non-State actors (e.g. families and private lawyers) do not interfere with the rights protected by article 13 and must provide training within the sector.[607]

Article 12 of the UNCRC provides that a child has the right to be heard in any judicial and administrative proceedings affecting them, either directly or indirectly, in line with

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[606] EU Agency for Fundamental Rights, *Access to Justice: An Overview of Challenges and Opportunities* (EU Agency for Fundamental Rights, 2011).

[607] Richard Whittle 'Access to Justice & article 13 of the UNCRPD' (16 May 2012) <http://www.era-comm.eu/UNCRPD/kiosk/speakers_contributions/111DV68/Whittle_Access.pdf> accessed 12 May 2020.

national law. This provision applies to all proceedings affecting the child, including those initiated by the child and those initiated by others.[608] A child's right to a remedy under the UNCRC obliges States parties to 'take all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts'.[609] This may include the right to assistance in repairing the consequences of a wrong or injury, and/or financial and/or moral compensation.[610] Article 40 of the UNCRC guarantees the rights of a child 'alleged as, accused of, or recognised as having committed an offence', and details the key principles and safeguards States Parties must put in place to guarantee effective access to justice and the right to a fair trial.[611]

9.2.1 Current Irish Context: Overview of law and policy

Civil Law

Access to the courts is protected as an implied personal right under article 40.3.1 of the Irish Constitution.[612] Article 42A of the Constitution enshrines a child's right to express their views and have their views given due weight based on their age and maturity in proceedings regarding their care. This right is limited to proceedings regarding guardianship, custody and adoption and proceedings which are initiated as a result of a fear for the child's welfare. This is not consistent with article 12 of the UNCRC, which clearly states that children's right to express their views extends to 'all matters affecting the child' and which the CRC Committee's General Comment No. 12 clarified is to be understood broadly.[613] It should be noted that under the Constitution the opportunity to be heard is limited to 'any child who is capable of forming his or her own view.' It is not clear how this provision might apply to children with cognitive disabilities who may be viewed as not capable of forming a view or expressing an autonomous opinion.[614] This is not consistent with the UNCRPD, the text of which removed this capability qualification and which states that children with disabilities should be provided with support to their express their views.[615]

In Ireland, children cannot independently institute legal proceedings. When a child wishes to take a case to enforce their rights they must do so through their 'next friend'.[616] A next friend is often a parent, guardian or adult third party appointed to act on behalf of the child. In such circumstances a solicitor is seen as acting for the next friend instead of for the child.[617]

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608 UN Committee on the Rights of the Child, General Comment No. 12 (2009): The Rights of the Child to be Heard (CRC/C/GC/12), para 33.

609 UNCRC, art 39.

610 United Nations Children's Fund, *Children's Equitable Access to Justice: Central and Eastern Europe and Central Asia* (May 2015) 26.

611 UNCRC, art 40.

612 FLAC (Free Legal Advice Centres) 'Access to Justice: a Right or a Privilege?' (July 2005) 9 <https://www.flac.ie/assets/files/pdf/access_to_justice_final.pdf> accessed 12 May 2020.

613 UN Committee on the Rights of the Child, General Comment No. 12 (2009): The Rights of the Child to be Heard (CRC/C/GC/12).

614 Jennifer Kline and Eilionóir Flynn, 'Access to Justice for Children with Cognitive Disabilities- Ireland Country Report' (Centre for Disability Law & Policy, National University of Ireland, Galway, 2013)

615 UNCRPD, art 7.

616 Rules of the Superior Courts, Order 15.

617 Children's Rights Alliance, 'Chapter 2: Access to Justice and Decision Making' in 'Making Rights Real- A Children's Rights Audit of Irish Law' (Dublin, 2015) 28.

Judges are provided with guidance on the law in relation to disability and accommodating persons with disabilities and children in a bench book entitled 'The Equal Treatment of Persons in Court' upon appointment. The bench book is not available to those outside the judiciary. It includes sections on "persons with disabilities, children/mental disability, physical disability and interpreters." [618]

In family law proceedings a child may be added as a party to the case where the Court is satisfied having regard to the age, understanding and wishes of the child and the circumstances of the case, that it is necessary in the interests of the child and in the interests of justice to do so.[619] Where a child is made a party to proceedings, the Court may also appoint legal representation for the child.[620] Alternatively, the Court may also appoint a Guardian ad litem (GAL) for the child if it is 'necessary in the interests of the child and of justice'.[621]

Beyond the provisions for the appointment of a GAL there is little regulation of their role, clarity regarding qualifications required or guidance available to them on supporting children with disabilities. There are currently 74 GALs operating in the State with the services provided by a range of voluntary bodies and groups of individuals.[622] Legislation to extend the application of GALs to hearings in relation to the Mental Health Act and other areas, the Child Care (Amendment) Bill 2019, lapsed with the dissolution of the Dáil.[623] The Bill is listed in the Government's Programme of Legislation for Autumn 2020.[624] However, it is not clear when it may be re-introduced as it not listed under the priority legislation or legislation expected to undergo Pre-Legislative Scrutiny (PLS) in the Autumn 2020 programme.[625]

According to the Children Act 1997, in any civil proceeding, the evidence of a child 'who has not attained the age of 14 years may be received otherwise than on oath or affirmation if the court is satisfied that the child is capable of giving an intelligible account of events which are relevant to the proceedings.'[626] This provision also applies to 'a person with mental disability who has attained the age of 14 years as it applies to a child who has not attained that age.'[627] While the term 'mental disability' is not further defined in the Act, it is likely that it refers to intellectual disability, acquired brain injury, autism and may extend to mental health issues. Therefore, children with these disabilities may give evidence in court proceedings only if the court finds they are 'capable of giving an intelligible account of events.' While the Act sets out some options for children giving evidence, including the use of intermediaries[628] and via live video-link,[629] it does not provide for any specific or additional supports which might be needed

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[618] Department of Children, Equality, Disability, Integration and Youth, *Draft Initial Report under the Convention on the Rights of Persons with Disabilities: Ireland* (Dublin: December 2020).

[619] Child Care Act 1991, s25.

[620] ibid.

[621] ibid, s26.

[622] Children's Rights Alliance, 'Report Card 2020' (Dublin 2020) 84.

[623] Houses of the Oireachtas, Child Care (Amendment) Bill 2019 (Bill 66 of 2019). <https://www.oireachtas.ie/en/bills/bill/2019/66/> accessed 10 June 2020.

[624] Office of the Government Chief Whip, Legislation Programme Autumn Session 2020 (15 September 2020) accessed 8 October 2020.

[625] ibid.

[626] Children Act 1997, s28(1).

[627] ibid, s28(3).

[628] ibid, s22.

[629] ibid, s21.

by children with disabilities, in order to communicate their account of events to the court.

Criminal Law

Article 38 of the Constitution of Ireland provides for the right to a fair trial, including the right to a trial by jury. In contrast with civil law proceedings, a child accused of a crime is always a party to the proceedings and entitled to legal representation. Children's criminal cases are heard in the Children's Court.[630] Despite a requirement in law for judges to undergo training before hearing cases in the Children's Court,[631] there is no formal training on youth justice available to the judiciary or detail on the type or content of the training required.[632] This has led to inconsistent decision making across the court and use of terminology or structures which leave it inaccessible to children.[633] Further, the lack of training means judges may not be equipped to deal with the range of issues impacting a child's life – including disability and mental health concerns.[634]

A number of different policy and legislative contexts shape access to the criminal justice system for children with disabilities in Ireland. [635] The Disability Act 2005 also places an obligation on public service providers (including the Gardaí, Director of Public Prosecutions and Courts Service) to make information and premises accessible.[636] The Court Service in Ireland also has a disability liaison officer who is responsible for providing assistance and guidance to persons with disabilities in accessing the court – which applies to both the criminal and civil justice systems.[637] Special measures are available for vulnerable witnesses, including children and those deemed to have a 'mental handicap' when giving evidence in court.[638] These measures include use of intermediaries in court, removal of wigs and gowns, and use of video link to give evidence.[639] Gardaí are required to treat children with respect and dignity and take into consideration any special needs related to disability whether they are a suspect[640] or a victim.[641] The Garda Diversity and Integration Strategy 2019 – 2021 identifies a number of key objectives which relate to interaction with minority groups.[642] This includes the development of a training programmes to increase Garda communication skills when interacting with minority groups.[643]

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[630] Children Act 2001, s71.

[631] ibid, s72.

[632] John O' Connor, 'Reflections on the Justice and Welfare Debate for Children in the Irish Criminal Justice System' (2019) 3 Irish Judicial Studies Journal 19 – 39.

[633] ibid.

[634] ibId.

[635] Claire Edwards, Gillian Harold, and Shane Kilcommins, 'Access to Justice for People with Disabilities as Victims of Crime in Ireland' (Cork: School of Applied Social Studies and Centre for Criminal Justice and Human Rights, Faculty of Law, University College Cork, February 2012).

[636] Disability Act 2005, s25 and s26.

[637] Courts Service of Ireland, *Accessibility* <https://beta.courts.ie/accessibility> accessed 10 June 2020.

[638] Criminal Evidence Act 1992 as amended by Criminal Justice (Victims of Crime) Act 2017.

[639] ibid.

[640] Children Act 2001, s55.

[641] Department of Justice and Law Reform, *Victims Charter and guide to the criminal justice system* (2010) <http://www.victimsofcrimeoffice.ie/en/vco/Entire%20Charter.pdf/Files/Entire%20Charter.pdf> accessed 10 June 2020.

[642] An Garda Síochána, 'Diversity & Integration Strategy 2019 – 2021' (2019) < https://www.garda.ie/en/crime-prevention/community-engagement/community-engagement-offices/garda-national-diversity-integration-unit/diversity-and-integration-strategy-2019-2021-english-v1-1.pdf> accessed 02 February 2021.

[643] ibid, 9.

There are no specific victims rights or victim support organisations that specialise in providing services to adults or children with disabilities or that note that they are trained on providing services to adults or children with disabilities.[644] The Criminal Justice (Victims of Crime) Act 2017 establishes minimum standards on the rights, supports and protection of victims of crime. The Act introduces a number of statutory rights for victims including the right to comprehensive information on the criminal justice system and victim support services,[645] and the right to receive information in clear and concise language and to interpretation and translation where necessary.[646]

According to Kline and Flynn, there are no reports that specifically assess the treatment of child witnesses and victims with cognitive disabilities in the criminal justice system in Ireland.[647] However, some cases reported in the media about the treatment of young adults with disabilities indicate the likelihood that crimes against children with disabilities are rarely prosecuted.[648]

9.2.2 Key barriers to the realisation of rights

Unable to commence legal proceedings to uphold rights

The lack of provisions to allow a child to take legal proceedings, without a 'next friend' under Irish law has been identified as a significant barrier to access to justice.[649] This is viewed as particularly problematic where there is a conflict between the parent's and the child's interests or where a child is separated from their parents, for example under the asylum system.[650] Children with disabilities may be particularly vulnerable as a minority group that frequently need to refer to the courts in order to enforce their fundamental rights and who may live in institutions or outside a family environment.

Lack of representation in family law and other proceedings

Despite laws allowing a child to be made a party in family law proceedings commentators argue that that there is a lack of information on its use in practice or its impact on children.[651] According to the Children's Rights Alliance, the provisions are vastly underused. [652] The level of discretion afforded to the Court regarding the appointment of a GAL has led to a very varied practice across the court system.[653] In other jurisdictions a Guardian is appointed by default, unless it would serve no useful purpose.[654] There is a considerable lack of guidance on the GAL's role, status

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[644] Jennifer Kline and Eilionóir Flynn, 'Access to Justice for Children with Cognitive Disabilities- Ireland Country Report (Centre for Disability Law & Policy, National University of Ireland, Galway, 2013) 36-37.

[645] Criminal Justice (Victims of Crime) Act 2017, s7.

[646] ibid, s22.

[647] Jennifer Kline and Eilionóir Flynn, 'Access to Justice for Children with Cognitive Disabilities- Ireland Country Report (Centre for Disability Law & Policy, National University of Ireland, Galway, 2013) 37.

[648] The case involved a young women with Down Syndrome who was prevented from testifying in court about her sexual assault. Juno McEnroe, 'Family want 'archaic' law overhauled' *Irish Examiner* (30 March 2010).

[649] Children's Rights Alliance, 'Chapter 2: Access to Justice and Decision Making' in 'Making Rights Real- A Children's Rights Audit of Irish Law' (Dublin, 2015) 28.

[650] ibid.

[651] Children's Rights Alliance, 'Report Card 2020' (Dublin, 2020) 86.

[652] ibid.

[653] Carol Coulter, 'Interim Report of the Child Care Law Reporting Project' (Dublin, 2013) 14.

[654] Children's Rights Alliance, 'Chapter 2: Access to Justice and Decision Making' in 'Making Rights Real- A Children's Rights Audit of Irish Law' (Dublin, 2015) 29.

or the necessary qualifications overall.[655] As noted above, currently a GAL may only be appointed where a child is not already a party to proceedings. Therefore, a child is not guaranteed access to an advocate who can explain procedures in a child-friendly manner when they are party. This may be particularly problematic for children with disabilities who may need additional measures or supports to ensure the court process is accessible.

Widespread lack of training

With the exception of some information for the judiciary in the form of a bench book, there is a widespread lack of guidance and training across the justice sector on how to make the process more accessible to children generally and in particular to children with disabilities is a fundamental barrier which must be addressed. O'Connor argues that the needs of a child should be determined on a case by case basis, including an 'individualised assessment in light of the specific circumstances of each child'.[656]

Insufficient supports for victims and witnesses

As noted above there is a lack of information concerning the treatment of child witnesses and victims with cognitive disabilities in the Irish criminal justice system.[657] Despite legislation setting out victims' rights and requiring supports to be made available, there are also no organisations which specifically support adults or children with disabilities who are the victims of or witnesses to a crime. [658] It is not clear whether existing organisations have training or guidance on how to support children with disabilities.

9.2.3 Measures to overcome identified barriers

Legislative measures

Legislative provisions detailing that children over a prescribed age can institute legal proceedings without the support of a parent or next friend should be enacted. This is found in other jurisdictions and allows children of sufficient age and maturity to institute proceedings and express their views in court.[659] In Ireland, this may be addressed through an amendment to existing legislation which provides for children and the courts, for example the Children Act 1997 or Children Act 2001, or it may also be dealt with under a new stand-alone comprehensive piece of legislation on children's rights. Such provisions must include adequate protections and supports for children with disabilities and should not include any assessments of capacity which are discriminatory on the basis of disability. They must also recognise the accessibility requirements of children with disabilities as parties or witnesses to a case and require that key documentation is provided in accessible formats. In Spain, a pilot project provided

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[655] Children's Rights Alliance, 'Report Card 2020' (Dublin 2020) 84.

[656] John O' Connor, 'Reflections on the Justice and Welfare Debate for Children in the Irish Criminal Justice System' (2019) 3 Irish Judicial Studies Journal 19 – 39.

[657] Jennifer Kline and Eilionóir Flynn, 'Access to Justice for Children with Cognitive Disabilities- Ireland Country Report (Centre for Disability Law & Policy, National University of Ireland, Galway, 2013) 37.

[658] ibid, 36-37.

[659] For example, the Children (Scotland) Act 1995, Section 11(10) includes a presumption that a child aged 12 or more has sufficient age and maturity to form a view in relation to instructing a solicitor and expressing his/her views in court.

Easy Read versions of the summons and subsequent verdict to people with intellectual disabilities to allow them to better understand the proceedings and the outcome.[660]

The previously lapsed GAL legislation must be re-introduced with reforms requiring all GALs to be trained to support children with disabilities and facilitate them to express their views and participate in process in an accessible manner.

Administrative and other measures

Training and guidance

Training must be provided to members of the judiciary and court staff, in particular those working in the area of youth justice, to ensure they understand the additional barriers children with disabilities face in accessing justice and are equipped to address them and provide the necessary accessibility measures. Gardai and other professionals which support victims of or witnesses to a crime must also be provided with support and training, in conjunction with disabled persons organisations, on how to support children with disabilities. This should be designed and delivered in conjunction with children with disabilities or their representatives in line with General Comment No. 7 of the UNCRPD. For example, in the United Kingdom toolkits are available to legal professionals on the fair and equal treatment of vulnerable people, including children with disabilities, in court.[661]

Data collection

Data must be collected on the experiences of children with disabilities in accessing justice in Ireland as either parties to a case, victims, witnesses, or third parties in family law proceedings. This should be used to inform any training or guidance provided to relevant parties. including the judiciary, court staff, legal professionals and GALs and findings should also inform future reforms.

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[660] Zero Project, 'Innovative Policy 2018 on Accessibility- Court verdicts and summonses in easy language' <https://zeroproject.org/policy/pol183054esp-factsheet/> accessed 1 September 2020.

[661] The Advocates Gateway, Toolkits <https://www.theadvocatesgateway.org/toolkits> accessed 1 September 2020.

9.3 Respect for privacy

Privacy is a fundamental human right articulated in all major international and regional human rights instruments and viewed as essential to autonomy and the protection of human dignity.[662]

Article 22 of the UNCRPD guarantees that persons with disabilities will not, regardless of the place of residence or living arrangements, 'be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation'. It states that the law should protect persons with disabilities against such interference or attacks.[663] Furthermore, article 31 of the UNCRPD requires that State Parties collect information, data and statistics to support the implementation of policies - when doing so they must obey safeguards to ensure confidentiality and respect for the privacy of people with disabilities.[664]

Article 16 of the UNCRC makes it clear that children and young people have the right to privacy. Similar to the UNCRPD, article 16 protects the child from unlawful or arbitrary interference with his or her privacy, family, home and correspondence and provides that a child has a right to protected from such interference under law. The UNCRC Committee provides that States should guarantee the protection of children's privacy rights in relation to information and communication technology (ICT) 'and develop effective safeguards against abuse without unduly restricting the full enjoyment of their rights'.[665]

9.3.1 Current Irish Context: Overview of law and policy

Article 40.3 of the Irish Constitution states that the State guarantees in its laws to respect, and as far as practicable, by its laws to defend and vindicate the personal rights of the citizen. The European Convention on Human Rights Act 2003 includes the requirement that the Data Protection Acts must be interpreted in a manner compatible with the ECHR.[666]

Under the Data Protection Act 2018, for the purposes of data protection, a child is anyone under the age of eighteen.[667] Children have the right to know how their data is used and stored and to have this information in a clear and accessible manner. In this regard it is not clear whether accessible refers to age appropriate accessibility or disability accessibility. The age of digital consent in Ireland is sixteen.[668] The age of digital consent refers to when a child may consent to the processing of their personal

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[662] Mark C. Weber, 'Protection for Privacy under the United Nations Convention on the Rights of Persons with Disabilities' (DePaul University, Chicago, IL: College of Law, 2017) 1-2.

[663] UNCRPD, art 22.

[664] Mark C. Weber, 'Protection for Privacy under the United Nations Convention on the Rights of Persons with Disabilities' (DePaul University, Chicago, IL: Faculty of Law, 2017) 1-2.

[665] UNCRC, *Report of the 2014 General Day of Discussion, Digital Media and Children's Rights* (OHCHR, 2014).

[666] Lawlor Partners, 'The Right to Privacy' (2016) <https://lawlorpartners.ie/case-for-compensation/the-right-to-privacy/> accessed 11 May 2020.

[667] Data Protection Act 2018, s29.

[668] Data Protection Act 2018, s31.

data by certain online services.[669] Therefore the consent of a parent or legal guardian is required for the processing of personal data of children under sixteen by information society services unless the services are 'preventative or counselling services'.[670] Under the Act children also have the right to be forgotten or to have their data erased on request.[671] The Act allows the processing of personal data for preventative or occupational medicine, medical diagnosis, the provision of medical care, treatment or social care, or the management of health or social care systems and services.[672]

The National Standards for Residential Services for Children and Adults with Disabilities require privacy to be respected through the maintenance of clear boundaries, the provision of care (including intimate care) in a sensitive manner, facilitating age appropriate opportunities to be alone and respect for the child's personal possessions.[673] They also require that where CCTV is used it does not intrude on privacy and that it is used based on a policy informed by relevant legislation.[674] The standards do not refer to digital or online privacy.

In HIQA's National Standards for Children's Residential Centres, respect for dignity and privacy is recognised under the standard of child-centred care and support.[675] The standards require respect for a child's privacy and dignity with regard to their personal space, personal communications, professional consultations, personal information and in the provision of intimate care, if required.[676] Personal belongings are also to be respected and opportunities should be given for each child to spend time by themselves in line with their development and age.[677] Limits of privacy should be in line with children's assessed needs, and the reason as well as with whom children's personal information is shared ought to be clearly explained.[678]

Respect for children's privacy is acknowledged in BOBF.[679] The strategy commits 'to continue to promote best practice by social media providers with respect to privacy controls and reporting mechanisms for abuse/bullying so as to better protect children online'.[680] However, there is no reference to this in the progress report so little is known of its status.[681] There is also no specific references to supporting children with

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[669] Data Protection Commission, *Public consultation on the processing of children's personal data and the rights of children as data subjects under the General Data Protection Regulation* (Dublin 2019) <https://www.dataprotection.ie/sites/default/files/uploads/2018-12/DPC_ChildrensRights_2019_English.pdf> accessed 26 May 2020.

[670] Data Protection Act 2018, s31(2).

[671] ibid s33.

[672] ibid s52.

[673] Health Information and Quality Authority, *National Standards for Residential Services for Children and Adults with Disabilities* (January 2013) 19 <https://www.hiqa.ie/sites/default/files/2017-02/Standards-Disabilities-Children-Adults.pdf> accessed 26 May 2020.

[674] ibid 28.

[675] Health Information and Quality Authority, *National Standards for Children's Residential Centres* (7 November 2018) 14 <https://www.hiqa.ie/reports-and-publications/standard/national-standards-childrens-residential-centres> accessed 28 May 2020.

[676] ibid 22.

[677] ibid.

[678] ibid.

[679] Department of Children and Youth Affairs, *Better Outcomes Brighter Futures-the National Policy Framework for Children and Young People 2014-2020* (Dublin, 2014).

[680] ibid 138.

[681] For more information see Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: Annual Reports* <https://www.gov.ie/en/collection/847593-better-outcomes-brighter-futures-annual-reports/> accessed 09 June 2020.

disabilities' privacy, particularly where they may use or require support to access online services.

9.3.2 Key barriers to the realisation of rights

Absence of guidance for online privacy

Despite commitments under the BOBF there is little to no information regarding the privacy controls and accessible complaints mechanisms for children with disabilities using social media. There is also a distinct absence of guidance or standards for ensuring the privacy of children with disabilities who require support to access online services. The lack of guidance is particularly evident in relation to residential settings, as noted above and is particularly concerning in light of the public health restrictions to combat COVID-19 and the increased reliance on online services to access education, supports, and communicate with family and friends. It may also pose a barrier for children with disabilities who wish to access information or complaints mechanisms online.

Lack of accessible information

A report from the Data Protection Commission has revealed that transparency information must be more child-friendly and relevant to child users of a platform or service.[682] While children must be provided with information on what their data will be used for in a clear and accessible manner, as set out above, there are no clear requirements or guidelines for how to ensure this is accessible to children with disabilities. This is of considerable importance to ensure children are informed of how their data is processed and also to ensure privacy for children with disabilities who wish to interact with such services without third party support.

Privacy within hospital settings

While there are guidelines for privacy in residential services there is less information or guidance available on respecting the right to privacy in a hospital setting, in particular in relation to children with disabilities who may require additional supports to attend clinics or communicate with healthcare professionals. The need to ensure a child or young person's privacy is respected from consultation to treatment has been highlighted by previous reports[683] and while some progress has been made in this regard it lacks information for children with disabilities.

9.3.3 Measures to overcome identified barriers

Legislative measures

New policy measures must be implemented to recognise the right to privacy for children, in particular children with disabilities, in a hospital or clinical settings from

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[682] Data Protection Commission, *Whose Rights Are They Anyway? Trends and Highlights from Stream 1 of the DPC's Public Consultation on Children's Data Protection Rights* (Dublin, September 2019) 10.

[683] Children's Rights Alliance, 'Report Card 2015' (Dublin, 2015) 58. Ursula Kilkelly and Eileen Savage, 'Child-friendly healthcare' (Dublin: Ombudsman for Children's Office, 2013) 22 <https://www.lenus.ie/bitstream/handle/10147/316410/ChildFriendlyHealthcareOCO.pdf?sequence=1&isAllowed=y> accessed 9 June 2020.

consultation through treatment and after care. This should include an update to the National Healthcare Charter for Children[684], with specific regard to the barriers faced by children with disabilities.

Justiciability of rights

The establishment of, or strengthening of existing, complaints mechanisms for breaches of privacy, such as those provided by the Data Protection Commission, and increased accessibility of such mechanisms for children, in particular children with disabilities. This must be in conjunction with accessible information campaigns to ensure children with disabilities are aware of their rights, how to enforce them and any supports available to access such mechanisms.

Administrative and other measures

The need to respect online privacy for children with disabilities, in particular those who require third party support, must be recognised under guidance and standards for residential services and support services.

Clear guidance must be provided, by the Data Protection Commission, on the requirements for accessible data processing and transparency information and how best to achieve this for all children with disabilities irrespective of impairment type. This must be drafted in consultation with children with disabilities or their representatives in line with General Comment 7 of the UNCRPD.

9.4 Freedom from exploitation

The terms exploitation, violence and abuse have no standard definitions. They are varyingly delineated by codes of conduct or criminal codes.[685] Freedom from exploitation is protected both within the UNCRC and the UNCRPD. Article 16 of the UNCRPD provides for freedom from exploitation, violence and abuse and is placed among other related articles concerning civil and political rights. Article 15 guarantees freedom from torture or cruel, inhuman or degrading treatment or punishment. The UNCRPD Committee's General Comment No. 3 on women and girls with disabilities highlights their higher risk of experiencing discrimination, exploitation, violence and abuse, in particular of a sexual nature, compared to women and girls without disabilities and men and boys with disabilities.[686]

Numerous rights provide for children's freedom from exploitation under the UNCRC. Article 19 places an obligation on States to take all appropriate measures to ensure children are protected from exploitation, abuse, neglect or maltreatment.[687] Subsequent provisions ensure children's right to be protected from a range of other forms of

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[684] Health Service Executive, *National Healthcare Charter for Children* (Dublin, 2018) <https://www.cuh.ie/wp-content/uploads/2019/11/HSE-National-Healthcare-Charter-for-Children-2018.pdf> accessed 27 August 2020.

[685] Marianne Schulze, 'Freedom from exploitation, violence and abuse of persons with disabilities Contribution to the Council of Europe Strategy on the Rights of Persons with Disabilities' (Strasbourg: Council of Europe, 2017) 7.

[686] UN Committee on the Rights of Persons with Disabilities, General comment No. 3 (2016): on women and girls with disabilities (CRPD/C/GC/3) para 31 and 35.

[687] UNCRC, article 19.

exploitation and abuse including exploitation in the labour market,[688] sexual exploitation and abuse,[689] and 'other forms of exploitation prejudicial to any aspects of the child's welfare'.[690] The UNCRC also has an Optional Protocol on the sale of children, child prostitution and child pornography.[691]

9.4.1 Current Irish Context: Overview of law and policy

There are a number of legislative provisions aimed at safeguarding children from violence or abuse. The Children Act 2001 provides for a broadly framed offence of child abuse.[692] Further, it is an offence to withhold information relating to a range of offences including abuse, assault, abduction or false imprisonment[693] of a child[694] or vulnerable person.[695] The Criminal Law (Sexual Offences) Act 2017 sets out a number of offences involving sexual exploitation of children,[696] and also introduces specific sexual offences against persons with certain disabilities which apply to both adults and children.[697] Organisations who have regular contact with families or children, directly or indirectly, have a responsibility to safeguard children.[698] However, a delay in responding to and investigating allegations is an ongoing concern. Of the 25,341 child protection cases 'open' to social work teams in the third quarter of 2019, around 20% of cases had not been allocated a social worker.[699] The data does not provide a breakdown for the number of children with disabilities affected.

The Inquiry into Protected Disclosures investigated allegations of physical and sexual abuse from 1989–2009 involving an intellectually disabled woman, known as 'Grace', while she was placed in a foster home.[700] A second report, explored abuse allegations by others who were cared for by the same foster family as Grace.[701] The report found that the HSE and Tusla should review their procedures regarding persons with disabilities placed in foster care and the reporting of abuse or neglect.[702] Despite these recommendations subsequent reports have found a lack of co-operation between the HSE and Tusla regarding children with disabilities in State care.[703] Although these

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[688] ibid, art 32.

[689] ibid, art 34.

[690] ibid, art 39.

[691] UN General Assembly, *Optional Protocol to the Convention on the Rights of the Child on the Sale of Children, Child Prostitution and Child Pornography*, 16 March 2001, A/RES/54/263.

[692] Children Act 2001, s246.

[693] Criminal Justice (Withholding of Information on Offences against Children and Vulnerable Persons) Act 2012, Schedule 1 and 2.

[694] ibid, s2.

[695] ibid, s3.

[696] Criminal Law (Sexual Offences) Act 2017, Part 2.

[697] ibid, Part 3.

[698] Children First Act 2015, s10; Tusla, *Children First: National Guidance for the Protection and Welfare of Children 2017* <https://www.tusla.ie/children-first/children-first-guidance-and-legislation/> accessed 3 June 2020.

[699] Tusla, *Quarterly Service Performance and Activity Report: Quarter 3 2019* (Dublin, 2019) <https://www.tusla.ie/uploads/content/Q3_2019_Service_Performance_and_Activity_Report_V1.0.pdf> accessed 10 June 2020.

[700] Paul Cullen, 'Who is 'Grace' and what happened to her?' *The Irish Times* (28 February 2017) <https://www.irishtimes.com/news/social-affairs/who-is-grace-and-what-happened-to-her-1.2992650> accessed 3 June 2020.

[701] Health Service Executive, *Disability Foster Care Report* (Dublin, 2015) <https://www.hse.ie/eng/services/news/media/pressrel/disability-foster-care-report.pdf> accessed 3 June 2020.

[702] ibid, 67.

[703] Ombudsman for Children's Office, *Molly's case: How Tusla and the HSE provided and coordinated supports for a child with a disability in the care of the State* (Dublin, 2018) <https://www.oco.ie/app/uploads/2018/01/OCO-Investigation-Mollys-Case-Jan-2018.pdf> accessed 10 June 2020.

reports focused on inadequate service provision and considerable progress has been made,[704] the lack of co-operation between two State bodies is concerning regarding the safeguarding of children with disabilities and ensuring their needs are met.

9.4.2 Key barriers to the realisation of rights

There has been considerable progress made in recent years regarding the number of children awaiting a social worker under Tusla. The OCO has also noted increased co-operation between the HSE and Tusla regarding children with disabilities.[705] However, concerns remain regarding the number of cases awaiting investigation and supports available for children with disabilities. There is also a lack of clear guidance on supporting children with disabilities who disclose abuse.

9.4.3 Measures to overcome identified barriers

Legislative measures

As suggested in section 9.2.3 above, the introduction of legislative amendments to provide specific support for children with disabilities to have their voices heard in court and to be able to recognised as parties to proceedings with an entitlement to legal representation, can be an important measure to respond to allegations of exploitation and abuse.

Administrative and other measures

Funding must be made available to increase the number of social workers available to work with children with disabilities who are at risk of abuse or neglect or have disclosed abuse. Guidance must be drafted on how to support children with disabilities who disclose abuse, including how to facilitate alternative communication and support the expression of views. This guidance may be primarily directed at social workers, designated officers or professionals working in the area however, some elements may also be relevant to others in a child protection role.

9.5 Freedom of information, expression, association

Freedom of information, expression, thought, conscience and religion are recognised across international human rights instruments, including the UNCRC and UNCRPD. Article 13 of the UNCRC provides for children's right to freedom of expression. It upholds children's rights to 'seek, receive and impart information and ideas of all kinds', in a range of formats as well as across borders.[706] The article also limits the restrictions that can be placed on this right. Closely connected to the right to freedom of expression are article 14, which provides for freedom of thought, conscience and religion; article 15, which upholds children's right to freedom of association; and article 17, which provides for children's right of access to appropriate information.

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[704] Ombudsman for Children's Office, *Molly Two Years On: Have Tusla and the HSE delivered on commitments to children with a disability in the care of the State?* (Dublin, 2020) <https://www.oco.ie/app/uploads/2020/01/Molly-Two-Years-On.pdf> accessed 10 June 2020.

[705] ibid.

[706] UNCRC, art 13.

Article 21 of the UNCRPD states that parties to the Convention must ensure that persons with disabilities, including children with disabilities, can exercise their 'right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice'.[707] The UNCRPD clearly articulates how States Parties must utilise accessible formats and technologies to provide information to the general public to ensure it is accessible for persons with disabilities at no extra cost.[708] It also states that persons with disabilities should be facilitated to use the method of communication of their choice in their official interaction with the State and that private entities and mass media are urged, when providing information to the public, including online information, to make their services accessible and useable by persons with disabilities.[709] States Parties also have a duty to recognise and promote the use of sign language.[710]

9.5.1 Current Irish Context: Overview of law and policy

Freedoms of expression and association are recognised in the Irish Constitution as fundamental personal rights under article 40.6. However, the Constitution places a number of limitations on these rights which the State may prescribe by law. Therefore, while all citizens have a right to express freely their convictions and opinions, the publication or utterance of seditious or indecent matter is an offence.[711] Freedom of association is limited by legislation to protect public order and morality.[712]

Information and Expression

The Irish Sign Language Act, when commenced, will place a duty on public bodies to 'do all that is reasonable' to provide sign language interpretation for persons to access statutory entitlements or services.[713] This should not cost the individual anything and may be via a remote or online interpreting service.[714] The Act would also allow a person to use Irish Sign Language in court and for the court to employ interpreters to ensure the person is not placed at a disadvantage.[715]

Under the Disability Act 2005 public bodies are required to communicate, as far as practicable, in forms that are accessible to persons with disabilities.[716] This includes using clear and easy to understand language for people with intellectual disabilities and ensuring documents and communications are accessible to screen readers and assistive technology for people with visual impairments. The Government has committed to promoting accessibility and universal design of public service information and ICT under the NDIS, 2017–2021.[717]

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[707] UNCRPD, art 22.

[708] ibid (a).

[709] ibid (b), (c) and (d).

[710] ibid (e).

[711] Constitution of Ireland, art 40.6.1.i

[712] Constitution of Ireland, art 40.6.1.iii

[713] Irish Sign Language Act 2017, s6.

[714] ibid.

[715] ibid s4.

[716] Disability Act 2005, s28.

[717] Department of Justice and Equality, *National Disability Inclusion Strategy, 2017-2021* (Dublin, 2017) 14.

Standard 1.5 of the National Standards for Residential Services for Children and Adults with Disabilities requires children living in residential services to have 'access to information in an accessible format that takes account of their communication needs'.[718] This includes that a child should have access to a copy of the standards, to support to communicate with others and to an advocate to facilitate communication and information sharing.[719] The rights of freedom of expression and opinion, and access to information form the basis of the key principle 'Fairness' within the Guidance on a Human Rights-based Approach in Health and Social Care Services,[720] published in 2019.

BOBF recognises that children with disabilities may need additional supports to ensure they can express their opinions.[721] The National Strategy on Children and Young People's Participation in Decision-Making provides that children must have access to all the relevant information and support to allow them to express their views. [722]

Children and young people in Ireland are highly engaged with digital media and technology as a means of access to information and expression. According to a 2012 study, social networking is a 'near universal' feature in the lives of Irish teenagers and an increasing part of the lives of younger children'.[723] However, this study did not disaggregate its data on the basis of disability. There is limited, if any, information available on children with disabilities, use of online technology in Ireland. However, a 2019 Council of Europe report on children with disabilities in the digital environment found that while the digital and online lives of children with disabilities are similar to their counterparts without disabilities, there are some distinct and important differences.[724]

The challenges and barriers faced vary significantly when considering the nature of impairment and children with disabilities were found to be disproportionately disadvantaged in terms of their ability to access and use the benefits of digital technology.[725] Children with disabilities also more frequently faced with discontinuity and disruption in their digital access.[726] While the report did not examine the law and policy in Ireland in particular, the findings underscore that greater attention needs to be paid by governments, the digital industry, schools and healthcare services to provide for the rights of children with disabilities in this area. The report also indicated that engagement with children with a diversity of disabilities is pivotal to ensure that their experiences are reflected in 'targeted laws and policies, as well as accessible services and digital design'. [727]

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[718] Health Information and Quality Authority, *National Standards for Residential Services for Children and Adults with Disabilities* (Dublin, 2013) 22.

[719] ibid.

[720] Health Information and Quality Authority, *Guidance on a Human Rights-based Approach in Health and Social Care Services* (Dublin, 2019).

[721] Department of Children and Youth Affairs, *Better Outcomes Brighter Futures-The National Policy Framework for Children and Young People 2014 -2020* (Dublin, 2014) 31.

[722] Department of Children and Youth Affairs, *National Strategy on Children and Young People's Participation in Decision-Making 2015 – 2020* (Dublin, 2015) 23.

[723] Brian O'Neill and Thuy Dinh, 'Social Networking Among Irish 9-16 Year Olds' (Dublin: Arrow@DIT, 2012).

[724] Council of Europe, *Two Clicks Forward and One Click Back- Report on children with disabilities in the digital environment* (Strasbourg, 2019) 5 <https://www.coe.int/en/web/children/-/-two-clicks-forward-and-one-click-back> accessed 3 June 2020.

[725] ibid 5.

[726] ibid 5.

[727] ibid 6.

Thought, conscience and religion

Children's right to freedom of thought, conscience and religion is protected under article 42.2.1 of the Constitution of Ireland. Under the Constitution, parents or guardians can provide direction on how this right is exercised. Many 'special schools' or schools providing supports for children with disabilities schools were traditionally, and continue to be, run by religious bodies or charitable organisations with a religious ethos. The prohibition of discrimination on religious grounds is provided for in the Equal Status Acts 2000–2012. However, the legislation allows schools with religious ethos to refuse entry to students or give preference to students on that ground if this is to preserve the school's ethos.[728] This was amended by the Education (Admissions to Schools) Act 2018 which requires schools to clearly set out their admission policies,[729] and limits the number of primary schools which can use religious ethos as grounds for refusing admission.[730] However the Act retains permission for post-primary schools to refuse admission on religious grounds in many cases.[731]

9.5.2 Key barriers to the realisation of rights

Barriers in accessing information

Children with disabilities face barriers in accessing information by the limited duties placed on public bodies and the key pieces of legislation in this area, such as the Irish Sign Language Act or the Disability Act 2005, which have yet to be commenced or are limited in their applicability.

A lack of information on experiences of children with disabilities in Ireland accessing information online is concerning, in particular with the increased use of digital technologies and online resources in light of the restrictions to combat COVID-19. Many services and information provided by both the public and private sector and information are now solely available online and therefore may not be accessible to children with disabilities.

Support to express their opinions

Despite recognition across multiple national strategies that children with disabilities may require support to express their opinions there is no guidance or resources available on how to achieve this in line with international best practice.

Religion

The CRA has highlighted that the provisions for freedom of thought and religion provided for under the Irish Constitution do not take into account the evolving capacities of the child and is therefore inconsistent with the UNCRC.[732] The largely denominational structure of the education system infringes on children's right to

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[728] Equal Status Act 2000, s7(c).

[729] Education (Admission to Schools) Act 2018, s61(1).

[730] Education (Admission to Schools) Act 2018, s61(2)(c).

[731] ibid.

[732] Children's Rights Alliance, 'Report Card 2016' (Dublin, 2016) 43-44.

freedom of religion.[733] This may have a particular detrimental effect on children with disabilities who often face a limited number of school options from the outset and for whom schools were traditionally, and often continue to be, run by religious bodies or charitable organisations with a religious ethos.[734]

9.5.3 Measures to overcome identified barriers

Legislative measures

The Irish Sign Language Act 2017 must be fully commenced to ensure public bodies have a duty to provide an interpreter to facilitate access to services and information for Deaf children. Provisions for accessible information under the Disability Act 2005 should be reformed to remove limitations such as 'as far as practicable' to ensure information provided to the public is accessible for children with disabilities.

The limits placed on refusal of admissions on the basis of religious ethos should be extended to post primary schools and the corresponding provision under the Equal Status Act should be reformed.[735]

Administrative and other measures

An increased number of non-denominational schools, inclusive of children with disabilities, must be funded and established to ensure freedom of religion. Resources to support children with disabilities to express their views and opinions must be made available. This should include guidance and training for the people who support children with disabilities in a professional capacity or may interact with them through their work, and the establishment of an independent advocacy service to support children who cannot or do not wish to be supported by parents, family or friends.

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[733] Children's Rights Alliance, 'Report Card 2016' (Dublin, 2016) 44.

[734] For an overview of the history of disability service provision and special schools in Ireland see Eilis Flood, *Assisting Children with Special Needs: An Irish Perspective* (Gill Education, 2013).

[735] Equal Status Act 2000, s7(c).

10. Conclusion: Summary of Key Barriers and Measures

Throughout this report, the key barriers and measures required fall in general into three main categories. The first is the separation of people with disabilities, and children, into different laws, policies and programmes, and the relative invisibility of children with disabilities within each of these measures. The second is the failure to actively involve children with disabilities in consultations on many existing laws, policies and programmes, and the failure to actively involve them in much of the existing research on the operation of these measures. The final issue this report highlights is the relative invisibility of children with disabilities in data – as data on the experiences of children is often not disaggregated by disability. These barriers, and the measures required to address them, are deeply interlinked, although each will now be addressed in turn.

Children with disabilities overlooked in many child- and disability-focused laws, policies and programmes

The implicit or explicit exclusion of children with disabilities in child- and disability-focused laws, policies and programmes is a pervasive barrier across almost all the areas covered in this report. Laws, policies and programmes designed to support people with disabilities are often focused exclusively on adults, and even where they do not explicitly state this, the focus on issues which do not affect children, such as employment, often indicates that children are at best a secondary consideration in measures directed at people with disabilities.[736] Further, in policies and programmes for people with disabilities which emphasise autonomy and independence e.g. in making decisions about one's own life, including the decision about where and with whom to live, ignore the specific challenges facing children with disabilities. One pertinent example of this is the fact that the supports offered under the Assisted Decision-Making (Capacity) Act apply only to adults,[737] even though children and young people with disabilities might also benefit from specific and tailored decision-making supports, especially during the transition from childhood to adulthood.

Similarly, with regard to children's rights, gaps relating to children with disabilities are evident even in national frameworks such as Better Outcomes Brighter Futures. While the framework repeatedly cites the UN Convention on the Rights of the Child,[738] it contains no reference to the UN Convention on the Rights of Persons with Disabilities, which provides more relevant and specific guidance with respect to the rights of

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[736] Department of Justice and Equality, *National Disability Inclusion Strategy 2017-2021* (Dublin, 2017); Department of Employment Affairs and Social Protection, *Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals and Commitments* (Dublin, 2020).

[737] Section 2, Assisted Decision-Making (Capacity) Act 2015.

[738] Department of Children and Youth Affairs, *Better Outcomes, Brighter Futures: The National Policy Framework for Children And Young People, 2014-2020* (Dublin, 2014)

children with disabilities. This omission may be in part explained by the fact that Ireland had not ratified the UN Convention on the Rights of Persons with Disabilities when the Framework was adopted, but it is nonetheless a concern that the existence of the Convention and its relevance to this group of children was not acknowledged.

In order to address these forms of exclusion, specific measures are required to actively include children with disabilities in the both child- and disability-focused laws, policies and programmes. This does not necessarily require the creation of stand-alone laws, policies and programmes directed only at children with disabilities, and in fact, such an approach may be counterproductive as it could lead to further marginalisation of this group. Instead, in most cases, the most effective measure required to address this barrier will be the addition of specific references, targets and actions to existing child- and disability-focused laws, policies and programmes which are directed at children with disabilities.

Failure to Effectively Include Children with Disabilities in Consultations and Research

As with the previous barrier, this problem is reflected in a number of areas throughout the clusters of rights and cross-cutting rights discussed in the present report. Children with disabilities are not a homogenous group. There is significant diversity within the community of children with disabilities and this means that different children will have different accessibility needs and require different supports in order to effectively participate in consultations on existing laws, policies and programmes, and to engage in research on the operation of these initiatives. While separate guidance on conducting research with children and with people with disabilities has been produced by the Department of Children and Youth Affairs[739] and the National Disability Authority[740] respectively, neither guidance document provides detailed advice on practical measures to involve children with different disabilities in research.

Measures to address this barrier require any research or consultation seeking to actively involve children with different disabilities to consider how specific access needs will be met, for example, for children with mobility impairments or physical disabilities, children with sensory disabilities, children who are blind/have low vision, d/Deaf children, autistic or neurodiverse children, children with experience of mental health services and children with intellectual disabilities. Many child-friendly research projects rely heavily on visual materials and methods (e.g. photovoice, rich pictures), and while this approach can be very effective for many children, an alternative approach will be needed for children who are blind or visually impaired. The use of sign language interpreters will be a vital support for Deaf children, but other children who are hard of hearing may need a different support, such as real-time captioning. Designing inclusive consultations and research takes time and resources, and also the input of children with disabilities themselves will be vital to understand how accessibility needs can be met. While different groups will require different forms of access, this should not be used as justification for further segregation based on impairment, and methods which are inclusive for all children with disabilities to have their say should be prioritised.

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[739] Department of Children and Youth Affairs, *Guidance for Developing Ethical Research Projects involving Children* (Dublin, 2012).

[740] National Disability Authority, *Ethical Guidance for Research with People with Disabilities* (Dublin, 2010).

Lack of Up to Date, Disaggregated Data on Children with Disabilities

For many of the areas addressed by this report, the lack of up to date, disaggregated data emerged as a key barrier to the realisation of rights for children with disabilities. In many contexts, without up to date data, it is difficult to make an evidence-based argument for reform, or to understand the exact impact of specific laws, policies and programmes on children with disabilities. Even where data does exist, it is often fragmented, and definitions of disability vary across different data sources, making it difficult to generate a comprehensive and holistic account of the experiences of children with disabilities. While Growing Up in Ireland and the CSO represent important sources of data on children with disabilities which can be compared through time, the lack of data on children with disabilities at all levels of the education system,[741] the lack of data on waiting lists for CAMHS,[742] and the lack of data on children with disabilities awaiting assessments of need under the Disability Act[743] represent just a few of the issues which remain to be addressed.

Measures to address this barrier should consider consolidating the CSO's authority to collect and disaggregate data, ensuring that consistent definitions of disability are used across data collection tools, and/or introducing legislative requirements for the responsible authorities including Government Departments to report to the Oireachtas annually on the data collected. In order to comply with human rights obligations, all data collection measures should also consult with and actively involve children with disabilities and their families, to understand better how this information can be gathered in a manner that respects the human rights of children with disabilities.

Finally, it is important to emphasise that this report represents only a starting point in our knowledge about the barriers facing children with disabilities in Ireland and what measures could be used to address these. The report's findings should therefore spark further discussion about how these barriers impact on children with disabilities and how they can be more fully addressed. Critical to any further action in this field will be the direct involvement of children with disabilities, and families who support them, in shedding further light on their lived experience and the measures which can effectively address the challenges they face.

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[741] Section 6.1.1.1 above.

[742] Section 8.2.1.2 above.

[743] Ombudsman for Children's Office, *Unmet Needs: A report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs* (Dublin, 2020).

Annex 1 – Clusters of Rights

Cross-cutting rights

- Equality and Non-discrimination (Article 2 CRC & Articles 2, 5 CRPD)
- Participation (Articles 3, 5, 12 CRC & Articles 3,7,12 CRPD)
- Accessibility (Article 23 CRC; Article 3, 9, 20 CRPD)

Cluster 1 – Development

- Education (Articles 28, 29 CRC & Article 24 CRPD) Including – early years, primary, secondary, access to third level/further ed and training, early school leavers
- Play – (Article 31 CRC & Article 30 CRPD)

Cluster 2 – Inclusion & Belonging

- Family & Alternative Care (Article 5, 9, 10, 20,21, 25 CRC & Article 23 CRPD)
- Housing/Community Living (Article 27 CRC & Article 19 CRPD)
- Built Environment &Transport (Article 9 CRPD)
- Minorities/Culture/Language (Article 30 CRC & Article 30 CRPD)

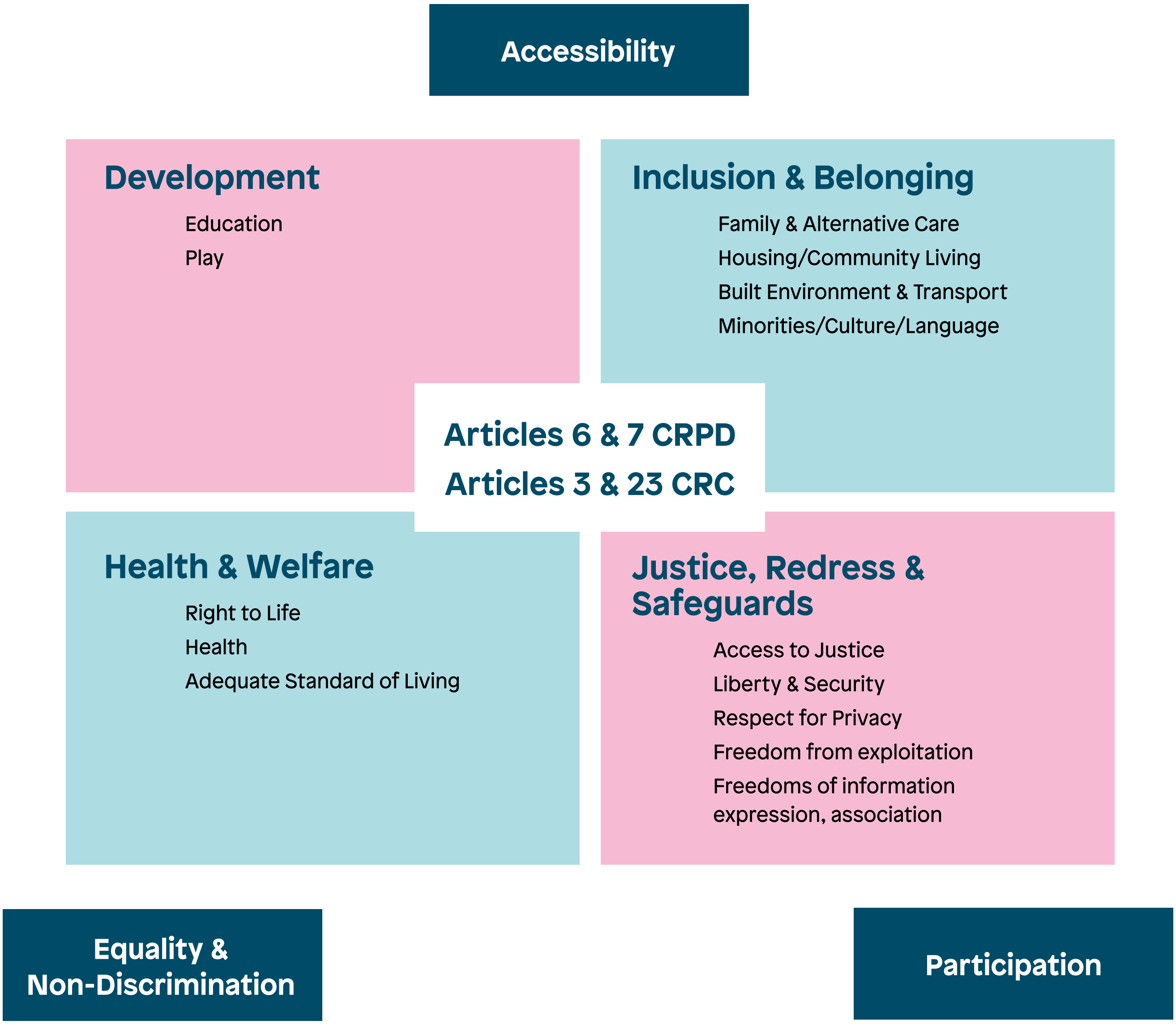
Cluster 3 – Health & Welfare

- Right to Life (Article 10 CRPD & Article 6 CRC)
- Health (Article 25 CRPD & Article 24 CRC) Including – primary/community care, mental health, physical health, rehabilitation/habilitation
- Adequate Standard of Living (CRC 26, 27; CRPD 28)

Cluster 4 – Justice/Redress & Safeguards

- Liberty & Security (Article 14 CRPD)
- Access to Justice (Articles 37, 39, 40 CRC & Article 13 CRPD)
- Respect for Privacy (Article 16 CRC & Article 22 CRPD)
- Freedom from Exploitation (Articles 19, 37 (a), 32, 33, 34, 35 CRC & Articles 15, 16 CRPD)
- Freedoms of Information Expression, Association (Articles 13, 14, 15, 17 CRC & Article 21 CRPD)

CRPD & CRC Cluster of Rights – Figure 1



Accessibility

Development

- Education
- Play

Inclusion & Belonging

- Family & Alternative Care
- Housing/Community Living
- Built Environment & Transport
- Minorities/Culture/Language

Articles 6 & 7 CRPD
Articles 3 & 23 CRC

Health & Welfare

- Right to Life
- Health
- Adequate Standard of Living

Justice, Redress & Safeguards

- Access to Justice
- Liberty & Security
- Respect for Privacy
- Freedom from exploitation
- Freedoms of information expression, association

Equality & Non-Discrimination

Participation

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