

**Civil Society Alternative Report in
response to the Fifth and Sixth
Combined Report of Ireland under the
UN Convention on the Rights of the
Child**

Disabled Women Ireland

December 2022

Introduction

Disabled Women Ireland (DWI) welcomes the opportunity to outline the lived experiences of disabled children in Ireland from our perspective as a disabled persons' organisation. DWI is Ireland's only national Disabled Persons' Organisation (DPO) representing disabled women, girls, non-binary and genderfluid people. We adopt a broad conceptualisation of disability in line with Article 1 UNCRPD. Therefore, our members self-identify as having '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.'

In this report, we focus on three core issues in relation to the rights of children and adolescents with disabilities – inclusive education, access to services and supports in the community and participation in decision - making. These areas, and the content therein, were identified in consultation with DWI members and following desk-based research. Unfortunately, constraints on funding and other resources limited the extent of our consultation and research. Under each area, we address Ireland's progress since it was examined by the Committee in 2016, issues of concern, and recommendations. DWI welcomes the Joint Statement by the CRC Committee and the CRPD Committee released earlier this year and we will draw on this statement when identifying barriers or failures to meet obligations.

Overview of the situation for children with disabilities in Ireland

As of Census 2016, there are 81,276 disabled children living in Ireland, representing 6.7% of the population¹. Of these 31,608 (38.9%) are female². Disaggregated data from the most recent census, held in April 2022, is not yet available. Indeed, data on children and young people with disabilities is generally very limited in Ireland.

Ireland has obligations to disabled children under both the UN Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD), the latter being ratified in 2018. However, neither Convention has been incorporated into domestic legislation, as it is required by Ireland's dualist approach regarding domestic and international law.

Disabled children living in Ireland experience significant barriers in all aspects of society. In their Concluding Observations the Committee recommended that Ireland establish a "*comprehensive strategy for the inclusion of children with disabilities*"³. Ireland has yet to address this recommendation and a recent report, commissioned by the Ombudsman for Children, highlighted that children with disabilities in Ireland are often not adequately considered in either disability law and policy or children's law and policy.⁴ Disability law and policy often focuses on the needs or lived experiences of adults with disabilities and law and policy which focuses on children does not consider the unique perspectives and intersecting identities of disabled children or the additional barriers they may face. For example, disability policy may focus on employment and overlook the rights, and additional barriers, for adolescents to gain work experience or children's policy which focuses on play and recreation will overlook the lack of personal assistance support available to disabled children outside

¹ Central Statistics Office, 'Census of Population 2016 Results Profile 9 - Health, Disability and Carers' accessed 03 December 2022.

² *ibid.*

³ Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland' (2016) UN Doc CRC/C/IRL/CO/3-4, para 48.

⁴ Catriona Moloney et al., 'Mind the Gap: Research on Barriers to the Realisation of Rights of Children with Disabilities in Ireland.' (Ombudsman for Children, Dublin, 2021).

of education. Therefore, the importance of considering the circumstances and rights of disabled children across all aspects of law and policy cannot be understated. DWI calls for the inclusion of children with disabilities in all aspects of policy and law to ensure no area is overlooked.

It must also be noted that the barriers to participation experienced by disabled children are more pronounced where the child is part of multiple marginalised groups, for example Traveller and Roma children, children living in Direct provision and children who are LGBTQIA+. While disabled children are protected from discrimination in accessing goods and services, including education, under the Equal Status Acts multiple or intersectional discrimination is not recognised. In addition, information or data relating to the experience of children with disabilities from these backgrounds is largely unavailable.

All the above challenges are underpinned by the fact that Ireland maintains a largely medical or charity model approach to disabled children and has not adopted a human rights-based model in line with both Conventions and as recommended by the Committee in their concluding observations⁵.

Key areas of concerns and recommendations

Access to Inclusive Education

In Ireland, disabled children are entitled to extra support to participate in education under the Education of Persons with Special Needs (EPSEN) Act 2004.⁶ However, and as previously highlighted by the UNCRC Committee in their concluding observations⁷, the Act has never been fully commenced or implemented. The Act contains a number of caveats, such as “*wherever possible*”, which permit a separate, segregated education systems for children with disabilities.

In recent years, there has been yearly increases in recent years the number of "special classrooms" - segregated spaces solely for disabled children, typically autistic children or children with intellectual disabilities, within mainstream schools. As of 2022, there are 2,535 such classrooms in schools across Ireland and 383 new special classes opened this year alone⁸. Special, completely segregated schools also exist in Ireland and as of 2021, 8,018 children are educated in such schools⁹. Many children with disabilities are on waiting lists for places in such schools or travel long distances to attend such schools because their needs cannot be met elsewhere. When disabled children access mainstream education, there is often insufficient support available to facilitate their full participation in education. Specific cohorts of disabled children are disproportionately affected by the lack of support and a lack of understanding of what is required for inclusive education. These include children with intellectual disabilities, autistic and otherwise neurodivergent children, d/Deaf children and children who communicate using Augmentative and Alternative Communication (AAC). For example, reports suggest a lack of understanding, training and resources for staff to support children

⁵ Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland' (2016) UN Doc CRC/C/IRL/CO/3-4 para 48(a)

⁶ Education of Persons with Special Needs Act 2004, s2.

⁷ Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland' (2016) UN Doc CRC/C/IRL/CO/3-4 para 47(e)

⁸ Minister of State for Education, Norma Foley TD., Joint Committee on Disability Matters debate, Discussion, Education and the UNCRPD, 20 September 2022 [35423/22]

⁹ Department of Education, Education Indicators for Ireland. December 2021

who use Augmentative and Alternative Communication (AAC).¹⁰ In their Joint Statement on the rights of children with disabilities, the CRPD and CRC committees state that *"the right to quality inclusive education is not compatible with sustaining two systems of education: a mainstream education system and a special/segregated education system"*.¹¹ The EPSEN Act is currently under review and DWI calls for a replacement of the Act which creates a *"comprehensive strategy for the inclusion of children with disabilities in mainstream education"* in line with the UNCRC Committees previous recommendations.¹²

Reduced Timetables

Placing children with disabilities on reduced timetables is a common practice in Irish schools. A report by Inclusion Ireland found that approximately one in four children with an intellectual or developmental disability had been placed on reduced timetables and this lasted for more than 20 days for half of these children¹³. This is despite guidelines from the Department of Education specifying that it should only occur in circumstances where it may be *"part of a transition or reintegration intervention, based on the needs of the individual students"* and should not be used *"as a behavioural management tool in the form of a sanction"*. In most cases, the justification given for placing a child on reduced timetables is that they are displaying 'challenging behaviour'. This is stigmatising for children with disabilities and does not recognise that what is often deemed 'challenging behaviour' is as a response to environmental factors, lack of accessibility and lack of support.

Seclusion and restraint

Seclusion and restraint also continues to be used as a response to 'challenging behaviour' or as a disciplinary measure in some Irish schools. Examples include children with disabilities being locked in a room, forcibly removed from spaces or held down. Such practices directly violate disabled children's right to education, bodily integrity, liberty and security and non-discrimination. They must be abolished and children should instead be accommodated based on their needs. Staff should be trained in a human rights-based approach to disability and an appropriate complaints and review mechanism put in place.

Individualised supports

Many disabled children who attend mainstream education do so with the support of a Special Needs Assistant (SNA). While the number of SNAs has increased year on year, our members, along with other disabled persons organisations such as ASIAm and schools themselves, have raised concerns that the number of SNAs overall continues to be insufficient. The result of this is that many students are left without the support needed to participate in education. Further, recent difficulties in sourcing

¹⁰ <https://www.irishexaminer.com/news/spotlight/arid-40948382.html>

¹¹ Committee on the Rights of the Child and Committee on the Rights of Persons with Disabilities, 'Joint Statement: The rights of children with disabilities' (2022)

¹² Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland' (2016) UN Doc CRC/C/IRL/CO/3-4, para 47(a)

¹³ Inclusion Ireland. Education, Behaviour and Exclusion The experience and impact of short school days 'on children with disabilities and their families in the Republic of Ireland. September 2019

substitute teachers, due to the rising cost of living and limited housing provision, has resulted in many SNAs being reassigned to fulfil teaching roles¹⁴.

Following the Committees concluding observations on the combined third and fourth reports of Ireland¹⁵ the Access and Inclusion Model (AIM) was introduced to provide access to the Early Childhood Care and Education (ECCE) scheme to children with disabilities in 2016. While many of the provisions under AIM welcomed in theory, our members have highlighted issues with its operation in practice. Under AIM guidelines funding can be provided to enable an Early Learning Centre to provide additional assistance in the preschool class. However, such assistance only decreases the child-to-adult ratio and does not ensure that a disabled child will receive the individualised support they may require. Additionally, individuals hired under this scheme can only provide support for 3 hours a day and there is no obligation for individuals to have any training in relation to disability, accessibility or equality. Therefore, while the scheme provides some support in pre-school it does not ensure that children with disabilities will have access to the individualised support they require in line with a human rights model.

Language rights

Irish Sign Language (ISL) is the first language of approximately 5000 Deaf people in Ireland. ISL was formally recognised in 2020 following the commencement of the Irish Sign Language Act 2017. In line with the Act, a scheme was created to provide ISL support to children in educational settings. Deaf advocates have raised concerns, following the initial phase of the scheme, about the strict selection criteria which adopts a medical rather than a rights-based approach. The scheme frames ISL as a communication tool, used only by those for whom other interventions have not worked and does not recognise ISL as a language. As a result, it fails to provide ISL support to Deaf children in the education system, and denies them their right to education under Article 29 of the CRC. It also denies them the right to their cultural and linguistic identity, in contravention of Article 30 of the CRC.

Recommendations:

In line with its obligations under Articles 28 and 29 UNCRC the State should

- Commit to using the results of the review of the EPSEN Act to outline a comprehensive strategy to achieve Ireland's human rights obligations to create a system of inclusive education for all.
- Provide funding to ensure that children with disabilities can be supported in mainstream schools
- Implement legislation which prohibits the use of 'reduced timetables' and seclusion and restraint.
- Extend the ISL scheme to recognise ISL as a language and provides support for interpreters in mainstream schools.
- Extend the AIM scheme in recognition of the individualised support which may be required by some children with disabilities and ensure all staff are properly trained.

¹⁴ Emma O'Kelly, 'Principals warn of 'devastating' impact of teacher shortage' (RTE News, 28 October 2022) available at <<https://www.rte.ie/news/education/2022/1028/1331821-teacher-shortage/>> accessed 03 December 2022.

¹⁵ Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland' (2016) UN Doc CRC/C/IRL/CO/3-4 para 47(c)

Access to Services and Support in the Community

The Committee has previously recommended that Ireland enacts all-inclusive legislation addressing the health needs of children.¹⁶ Ireland has yet to enact such provisions and access to services and supports in the community continues to be an enormous issue for disabled children. Many services continue to be provided by voluntary service providers, often charitable or other entities, and are reliant on diagnosis rather than need. This does not align with a human rights model of disability. Across sectors children with disabilities face extensive waiting lists and delayed access to essential supports and early intervention services. This impacts the holistic development of the child, their inclusion in the community and their rights under Article 23 and 24 UNCRC, among others.

Over 93,000 children were on waiting lists for community-based services such as physiotherapy, speech and language therapy in May and June this year. A high number of those, almost 30,000, were waiting for over 12 months.¹⁷ This was across sectors with over 4,000 children on waiting lists for Children and Adolescent Mental Health Services (CAMHS) and 540 of those were waiting over 12 months.¹⁸ Some services, and parts of the country, experience more extensive delays than others with many describing access to essential health services and assistive technology as a 'postcode lottery'. For example, waiting lists for speech and language therapy were among the longest with 14,862 children on the waiting list for initial assessment, 7,151 waiting for initial therapy and 9,891 awaiting further therapy.

In its concluding observations on the combined third and fourth reports of Ireland the Committee noted the socio-economic disadvantages faced by certain groups of children and families and called on Ireland to address them¹⁹. Many parents, families or caregivers' only recourse due to the extensive waiting times is to access essential services, in particular early intervention services, for their disabled children in the private sector. Therefore, children whose parents cannot afford to do this are at a particular disadvantage. Further, many children face significant delays in obtaining a diagnosis, often essential to accessing services, and having their needs assessed. Consequently, these figures, which only include those who are currently waiting for services, do not show the full extent of the issues.

When children do access services there is often a lack of coordination across services or sectors which impacts the efficacy of the support provided. Disability services, mental health services, primary care and acute care while funded by the Health Service Executive may be provided by a mixture of voluntary service providers and State actors. There is no structured transition process from child to adult services in the health sector or clear linked pathways between services. Progressing Disability Services for Children and Young People is a programme which aims to address many of these issues with consistency and access. However, there are significant issues with its implementation, recruitment of staff and engagement with children and families.²⁰ In August 2022, over 17,000 children

¹⁶ UN Committee on the Rights of the Child, Concluding Observations on the Second Periodic Report Ireland 2006 (CRC/C/IRL/CO/2) para. 45.

¹⁷ The Irish Times, 'More than 110,000 children on therapy waiting lists; Number of children on all forms of public health waiting lists reaches 220,000' (August 18, 2022).

¹⁸ <https://www.hse.ie/eng/about/personal/pq/2022-pq-responses/july-2022/pq-41001-22-david-cullinane.pdf>

¹⁹ Committee on the Rights of the Child, 'Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland' (2016) UN Doc CRC/C/IRL/CO/3-4 para 50

²⁰ Inclusion Ireland, Progressing Disability Services for Children and Young People: Patient Experience Survey Report (February 2022) <<https://inclusionireland.ie/wp-content/uploads/2022/03/Inclusion-Ireland-Progressing-Disability-Services-Report-March-2022.pdf>>

were waiting for initial contact from a specialised Child Disability Network Team (CDNT) under the programme.²¹

Under the Disability Act 2005, children are entitled to have their needs for services and supports assessed.²² The Assessment of Need (AON) process is subject to clear guidance on when the review will take place, how it will be conducted and that it must not consider the cost of or capacity to provide services but the service needs of the child. It does not, however, provide an entitlement to services and instead requires the drafting of a service statement which outlines how those needs will be met. The process is subject to significant criticism following increased delay for assessments, assessments by untrained staff and a lack of consistency in approach across the country. The AON does not consider the disabled child as a whole and instead focuses on a medical model approach to disability and services. It does recognise changes made elsewhere to policy, such as Progressing Disability Services for Children and Young People, or obligations to support the holistic development of the child under the UNCRC and UNCRPD. In general, the 2005 Act is outdated, does not conform with the human rights model of disability in its definition or provisions and is therefore in need of review.

Recommendations

In line with its obligations under Articles 23 and 24 UNCRC the State should

- Adopt all-inclusive legislation addressing the health needs of children
- Recruit staff and provide the necessary funding and supports to address the long term and continuing issue of waiting lists
- Commit to the funding and implementation of the Progressing Disability Services for Children and Young People in line with the human rights model
- Review and reform the Disability Act 2005 in line with the human rights model recognising the broad support needs of children with disabilities for community inclusion.
- Implement a comprehensive framework for transition from child to adult services including obligations to support young disabled people

Participation in decision-making processes

A child's right to express their views and have them given due weight is recognised in a number of ways across law and policy in Ireland. However despite this, and an acknowledgement that Article 12 UNCRC applies without discrimination, disabled children often do not have their views heard. Law, policy, and practice regularly overlooks the unique perspectives of children and young people with disabilities, the supports they may require to express their views, and the additional efforts required to ensure processes are accessible and inclusive.

The National Framework for Children and Young People's Participation in Decision-making is designed to provide 'practical tools to ensure that children and young people are included in decision-making

²¹ Darragh Bermingham, 'Over 17,000 children awaiting first contact from short-staffed child disability teams' (Irish Examiner, 04 August 2022).

²² Disability Act 2005, s7.

in all settings'.²³ It recognises children and young people's right to express their views under Article 12 CRC and that disabled children and young people should have access to disability and age appropriate assistance. Despite this, recent consultations on the next Government policy framework for children and young people did not have materials available on the website in alternative formats, such as Easy Read, which would make the process accessible for children and young people with disabilities. The submission process did accept drawings and pictures but did not provide the information or question in accessible formats. In general, the provision of materials in accessible or child-friendly formats are not embedded in practice and are not made available as standard for consultations on legislation or policy.

In relation to individual decision - making, while a child's right to have their views considered when their best interests are determined is found in legislation relating to guardianship, custody, access, adoption and care proceedings²⁴, it does not recognise the support for communication or the need to facilitate any mode of communication. The provision of information in accessible formats is ad hoc or sporadic in nature and children and young people often note that it depends on the individual professional or setting if this occurs.

Overall, Ireland does not have a clear statutory framework which recognises adolescents evolving capacities in relation to consent to medical treatment. This is despite recommendations from the Irish Law Reform Commission in 2011 in this regard and inconsistency regarding consent to physical vs. mental healthcare highlighted. The Assisted Decision - Making (Capacity) Act 2015 is Ireland's new legislative framework regarding decision making capacity and support. It will embed the functional test of capacity in Irish legislation as well as a range of supported decision-making options and safeguards. However, the Act does not apply to those under 18 and adolescents will not be in a position to benefit from any of its supports or safeguards. This is despite 16 and 17 years being understood, based on an interpretation of criminal law, as allowed to consent to medical treatment and subject to capacity tests. While the Act does not conform with the requirements of the UNCRPD and should be amended appropriately, its exclusion of young disabled people is discriminatory and may place them at a significant disadvantage if they have their capacity assessed. The Act provides clear structures and safeguards for the process including the provision of information in a way that a person can understand, obligations on intervenors to take all practicable steps and understands communication of decisions in a broad sense. Neither of these are available to young people subject to capacity assessments under the current system.

Recommendations

In line with its obligations under Article 12 UNCRC the State should

- Ensure access to support and a wide variety of communication methods is embedded across law and policy to facilitate children and young disabled people to express their views on individual or personal decisions
- Adopt a systematic approach to the provision of alternative, accessible formats of documents to ensure children and young people can participate in consultation processes and express their views on an equal basis with others

²³Department of Children, Equality, Disability, Integration and Youth, National Framework for Children and Young People's Participation in Decision-making (Government of Ireland, Dublin, 2021)
<https://hubnanog.ie/wp-content/uploads/2021/04/5587-Child-Participation-Framework_report_LR_FINAL_Rev.pdf>

- Introduce a clear, comprehensive framework outlining when a child may consent to medical treatment and outlining obligations to provide support and reasonable accommodation for disabled children and young people