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An tIonad Dlí & Beartais Míchumais
Centre for Disability Law & Policy

Submission on the
The Rights Based Approach and Disability
Legislation

to the

Joint Committee on Disability Matters

April 2023

Introduction

The Centre for Disability Law and Policy (CDLP) welcomes the opportunity to make this submission to the Joint Committee on Disability Matters. We also welcome the Committee's commitment to undertaking a human rights based review of disability legislation. The Committee on the Rights of Persons of Disabilities (CRPD Committee) has repeatedly called for States Parties to harmonise all legislation and policy with the human rights model of disability. As such this is a central element of Ireland's obligations to implement the UN Convention on the Rights of Persons with Disabilities (CRPD).

The UN Office of the High Commissioner for Human Rights (OHCHR) has developed indicators to guide States on actions and measures to be taken in implementing the CRPD and facilitating the assessment of progress. There are indicators for each Article in the Convention and they have been developed based on the human rights standards (e.g., General Comments). We will draw on these indicators to review the Disability Act 2005, its intersection with the Education for Persons with Special Educational Needs Act 2004 (EPSEN Act 2004) and comment on the changes required to the overall legislative framework for a rights based approach in line with the CRPD.

Overall Framework

The overall implementation of the CRPD and adoption of a human rights based approach requires States to withdraw any reservation or declaration which are incompatible to the object and purpose of the treaty (*Indicator 1/4.1*). States should also ratify the Optional Protocol to the Convention (*Indicator 1/4.2*). Ireland has entered 3 reservations or declarations to the CRPD on Articles 12, 14 and 27. It also has yet to ratify the Optional Protocol despite repeated calls by the Joint Committee and other stakeholders to do so.

While it is understandable that the Committee would focus on two primary pieces of legislation (the Disability Act and the Education for Persons with Special Educational Needs Act) for an initial human rights based review, in order to fulfil Ireland's obligations under the CRPD a comprehensive programme of reform of all laws and policies related to the rights protected in the Convention must be undertaken. The aim of such a programme must be to harmonise all legislation with the Convention and ensure the rights therein are applicable and enforceable at a domestic level (*Indicator 1/4.3*). The CRPD Committee and the OHCHR indicators both clearly state that the obligations under the CRPD do not only apply to disability specific legislation and that disability rights should be mainstreamed across laws and policies.

Any legislation enacted should be in line with the purpose, definitions, principles and general obligations of the CRPD (*Indicator 1/4.4*). This requires States to eliminate the charity and medical models of disability and fully enshrine the human rights model in law and policy. A

key part of this is ensuring that legislation includes the conceptualisation of disability as set out in Article 1 CRPD. The definition or conceptualisation of disability varies across Irish law and policy. However, the definitions employed are consistent in their focus on the medical issues or impairments and they tend to locate the issues within the individual disabled person. They do not adopt a conceptualisation in line with Article 1 CRPD which recognises that disability is as a result of impairments interacting with various barriers in society. Other general principles under the Convention include respect for inherent dignity, individual autonomy and independence, full and effective participation and inclusion in society, accessibility and respect for difference and acceptance of persons with disabilities as part of human diversity and humanity. These should be the cornerstones of any legislative reform.

A national strategy should be adopted (*Indicator 1/4.5*) which outlines the have timeframes, indicators, benchmarks. The National Disability Inclusion Strategy 2017 – 2021 was extended to apply to 2022 and now requires a successor. This provides an excellent opportunity to put an action plan or strategy in place which outlines how Ireland intends to harmonise its laws with with the CRPD. It is crucial that a clear timeframes and benchmarks for progress are included in such documents. Alongside the indicators for structural reform the OHCHR provide indicators to measure progress in the process and outcomes of implementing the CRPD. These could also be incorporated into a national strategy and form the basis of an ongoing assessment of progress.

States Parties have an obligation to closely consult and actively involve persons with disabilities, including children with disabilities, and their representative organisations in the development and implementation of legislation and policies to implement the CRPD (Article 4.3). The OHCHR has outlined that this requires legal or regulatory provision(s) which establish inclusive accessible procedures and mechanisms for their involvement (*Indicator 1/4.9*) and protection of the right to freedom of association and protection against intimidation, harassment and reprisals, particularly when expressing dissenting opinions (*Indicator 1/4.10*). Finally, requiring the participation of disabled persons organisations is not sufficient. Funding should be made available to enable them to meaningfully participate in these reform processes and to support the development and strengthening of the organisations (*Indicator 1/4.11*).

Disability Act 2005

The Disability Act 2005, when initially introduced, aimed to ‘significantly advance the position of people with disabilities’ in Irish society and references to a rights, in relation to the assessment of need and service statements in particular, were common in debates.¹ However, its subsequent application in the context of assessments of need and accessibility

¹ Dáil Deb 4 November 2004, vol 591, col 1373

of public services has highlighted that it does not meet this aim. Indeed the Act's focus on assessing needs rather than a right to be included in the community and access to support undermines the Ireland's commitment to disability rights under the CRPD. This is further exacerbated by the fact that many of the provisions in the suite of measures introduced alongside the Act (e.g., the EPSEN Act 2004 and a disability strategy) were never fully commenced or implemented. Therefore an overhaul of these area of law is required to ensure the rights of persons with disabilities is respected.

The first step in reforming any piece of legislation is to determine its overall goal and what issues it seeks to address. At the core of the Disability Act 2005 is access to services and supports for persons with disabilities. If the purpose of the reform is to address access to services and supports for persons with disabilities then a rights based review of the Act must be based on Article 19 CRPD and other relevant provisions such as Article 25, 26, and 28. Legislation to replace the Disability Act should recognise the right of all persons with disabilities to live independently and be included in the community ensuring their individual autonomy and control over their life, regardless of impairment and required level of support. (*Indicator 19.1*). This should be an enforceable right and a plan with timeframes and measurable goals to implement this right, including the availability of a range of housing options and support services should also be drafted (*Indicator 19.2*).

In order for this right be meaningful in practice, a broad range of supports must be available to persons with disabilities. A report by the UN Special Rapporteur on the Rights of Persons with Disabilities in 2017 described support as including a wide range of formal and informal interventions which can include mobility aids and assistive devices and technologies, personal assistance; support in decision-making or communication support, living arrangements services for securing housing and household help.² The current assessment of needs process is confined to the health and education needs of an individual.³ It does not consider the broader support or service requirements for persons with disabilities to live independently and be included in their community. The 'purpose, design and/or outcome of supports must be to facilitate the inclusion and participation of persons with disabilities in the community, preventing isolation and segregation from others.' A recent report by the UN Special Rapporteur on the Rights of Persons with Disabilities, Professor Gerard Quinn, highlighted the need to transform disability services and supports.⁴ This transformation requires a shift to services based on a philosophy of autonomy and social inclusion for persons with disabilities.

Despite the broad conceptualisation of services and supports they are underpinned by a number of key principles – services and supports should not be solely based on the physical

² United Nations, Report of the Special Rapporteur on the rights of persons with disabilities (20 December 2016) UN Doc. No. A/HRC/34/58.

³ Disability Act 2005, s8.

⁴ United Nations, Transformation of services for persons with disabilities Report of the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn (28 December 2022) UN Doc. No. A/HRC/52/32

or care needs of the individual and must instead focus on a person's requirements to be included in the community; persons with disabilities should have choice and control over their supports; services and supports should be accessible to all persons with disabilities without discrimination of any kind; services and supports should be available within geographical reach for everyone and be transferable within the different regions of the State. Ideally a reform of the Disability Act 2005 would occur alongside a broader co-design and transformation plan of how and where services and supports for persons with disabilities are delivered in Ireland using these principles, alongside others in the CRPD, as its base. The Special Rapporteur has highlighted a number of steps that can be taken to achieve this including co-design of services with persons with disabilities and their families and broader implementation of a personalised budget or direct payments model. The report also identifies the use of personal support plans, identifying formal and informal support (such as that provided by families), and how this support will be used to achieve goals over time or overcome challenges.

The 2005 Act also sets out to provide for access to public buildings and services for persons with disabilities and the preparation of sectoral plans. Access to public and community services is a key element of Article 19 CRPD and also links with Article 9 – Accessibility. The indicators for these articles set out that legislation should be enacted which provides for the right to access, on an equal basis with others, to the physical environment, transportation, services, information and communications, and other facilities and services open or provided to the public, in both urban and rural areas (*Indicator 9.1*). The successful achievement of this will also require all public services to adopt uniform national accessibility standards (*Indicator 19.12*) and an initial audit to identify barriers to accessing public services by persons with disabilities. This audit should include the physical environment and transportation, buildings and facilities and services open to the public, and ICT technologies and should be repeated on a periodic basis with the close involvement of persons with disabilities. (*Indicator 9.7 iii*).

The Disability Act 2005 recognises that public bodies should communicate in manner that is accessible to the person concerned if they have a hearing or visual impairment.⁵ These provisions do not recognise the developments in technology since the enactment of the 2005 Act which have greatly increased communication by an electronic means and the use of government websites etc. to provide important information. It also does not recognise that other disabled people, beyond those with hearing or visual impairments, may require information in accessible formats and where it does it only prescribes plain language formats and overlooks others e.g., Easy Read. Legislation regulating government information and communications intended for the general public must guarantee full access of public sector websites and apps, and availability of government information in alternative formats (*Indicator 9.6*).

⁵ Disability Act 2005, s28

Education for Persons with Special Educational Needs Act 2004

In addition to a comprehensive reform of the Disability Act, as part of the development of a holistic legislative framework to protect the totality of rights contained in the CRPD, legislation should be enacted that ensures inclusive education for all students, and moves away from the use of medicalised or impairment-based assessments to access supports in the education system. The right to inclusive education in the CRPD applies to students with disabilities in public and private settings across all levels of education – pre-school, primary, secondary, and tertiary education (*Indicator 24.1*). The OHCHR has provided further detail on what should be included in the legislation following an analysis of human rights standards. Legislation on inclusive education should include a clear definition of inclusive education consistent with the CRPD, the prohibition of discrimination on the basis of actual or perceived impairment, the obligation to provide reasonable accommodation and support, the right of all learners to be taught in their mother tongue (e.g., sign language, indigenous/minority languages) as well as a “non-rejection” clause ensuring no student is excluded from education on the basis of disability.

Programmes should be established for the early identification of children with disabilities and their support needs for their effective participation in mainstream schools. (*Indicator 24.4*). The assessment of need process under the Disability Act if properly implemented, resourced and undertaken in a rights based manner could have provided the basis for this process. It was reportedly initially designed to apply to children from 0 - 5 years of age with the EPSEN Act 2004 designed to operate once the child reached school going age. However, numerous provisions under the EPSEN Act 2004 remain uncommenced and the Joint Committee on Children, Equality, Disability, Integration and Youth has pointed out that this leads to an increase in applications under the Disability Act.⁶ As a result the assessment of need process, which is not operating on a human rights based framework, is subject to considerable delays and arguably not fit for purpose.

In general however, the transition to an inclusive education system is not marked by focusing solely on the individual needs of the child and how they can fit within the existing education system. The CRPD Committee in General Comment No. 4 have clearly stated that achieving the right requires a ‘transformation in culture, policy and practice’ to create accessible and inclusive environments and curricula.⁷ This requires States Parties to introduce a universal design approach across institutions and programmes. It does not, however, prevent them from providing individual supports or reasonable accommodation to students as required.

⁶ Joint Committee on Children, Equality, Disability, Integration and Youth, ‘Report on Assessments of Need for Children’ (Houses of the Oireachtas 2023).

⁷ Committee on the Rights of Persons with Disabilities, General comment No. 4 (2016) on the right to inclusive education. UN Doc. No. CRPD/C/GC/4 para 9.

The CRPD Committee recommends the use of individualised education plans which set out the reasonable accommodation and support requirements of the student to achieve this.⁸ According to Ireland’s human rights obligations, these plans should be regularly reviewed and developed with the direct involvement of the student. Support in this context could include the provision of learning materials in alternative/accessible formats, communication, an assistant, movement breaks, and accessible technology. Students, and their parents where appropriate, should also be in a position to complain if the plans are not appropriate or are not respected. The EPSEN Act does refer to education plans and the development of individualised education plans; however, these sections have not been fully commenced and are not compliant with the CRPD in their approach. They do not for example require students or their parents to be involved in their development, or focus on reasonable accommodation or support as a matter of right.

Conclusion

In summary, the review of the assessment processes for the Disability Act and EPSEN Act need to take place as part of a broader scoping exercise, which examines whether the legislation which formed the core components of Ireland’s National Disability Strategy remains fit for purpose in light of the human rights obligations Ireland now has as a State Party to the CRPD. This holistic and comprehensive review process must include the meaningful participation of persons with disabilities and their representative organisations to determine the priorities for Ireland’s legislative framework into the future. The CDLP remains at the disposal of the Oireachtas Disability Matters Committee and can provide additional research to support the recommendations in this submission upon request.

⁸ *ibid*, para 33.

Resources

Office of the High Commissioner for Human Rights, SDG-CRPD resource package, available at <<https://www.ohchr.org/en/disabilities/sdg-crpd-resource-package>>

United Nations, Transformation of services for persons with disabilities Report of the Special Rapporteur on the rights of persons with disabilities, Gerard Quinn (28 December 2022) UN Doc. No. A/HRC/52/32. Available at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G22/613/79/PDF/G2261379.pdf?OpenElement>>

United Nations, Report of the Special Rapporteur on the rights of persons with disabilities (20 December 2016) UN Doc. No. A/HRC/34/58. Available at <<https://documents-dds-ny.un.org/doc/UNDOC/GEN/G16/436/64/PDF/G1643664.pdf?OpenElement>>