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.

October 2020

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for children

Abbreviations

HSE	Health Service Executive
NCSE	National Council for Special Education
HIQA	Health Information and Quality Authority
OCO	Ombudsman for Children’s Office
2002 Act	Ombudsman for Children Act, 2002
AON	Assessment of Need
UNCRC	United Nations Convention on the Rights of the Child
UNCRC Committee	United Nations Committee on the Rights of the Child
NDS	National Disability Strategy
2005 Act	Disability Act, 2005
EPSEN Act	Education for Persons with Special Education Needs Act, 2004
2007 Regulations	Disability (AONs, Service Statements and Redress) Regulations 2007
CHO	HSE Community Healthcare Organisation
NEPS	National Educational Psychological Service
SOP	Standard Operating Procedure
PDSCYP	Progressing Disability Services for Children and Young People 2010
SLT	Speech & Language Therapy
ASD	Autism Spectrum Disorder
2003 Act	European Convention on Human Rights Act, 2003
EU	European Union
EU Charter	European Union Charter of Fundamental Rights
ECHR	European Convention on Human Rights
ESC	European Social Charter
ESC Committee	European Committee of Social Rights
UN	United Nations
ICESCR	International Covenant on Economic, Social and Cultural Rights
CESCR Committee	UN Committee on Economic, Social and Cultural Rights
CRPD	United Nations Convention on the Rights of Persons with Disabilities
CRPD Committee	United Nations Committee on the Rights of Persons with Disabilities
IDG	Inter-Departmental Group

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Acknowledgments

We would like to thank the children and young people who spoke with us and gave us permission to tell their stories, and the parents who continue to fight for what should be a right for their children.

We would also like to acknowledge the Department of Education and Skills (DES), the Health Services Executive (HSE), the National Council for Special Education (NCSE), the National Educational Psychological Service (NEPS), the Health Information and Quality Authority (HIQA), Inclusion Ireland, KOD Lyons Solicitors, and Dr Conor O'Mahony, the Special Rapporteur on Child Protection, for their engagement on this important issue.

We dedicate this report to the children waiting for an assessment of their needs, and to the parents and guardians who advocate tirelessly for their child's statutory right to receive services that will allow them to reach their full potential.

Foreword

by Dr Niall Muldoon, Ombudsman for Children

No parent expects their child to have a disability. In many cases it is the parent who first notices that their baby may not be reaching their developmental milestones or who may notice that they appear different in some way to their peers. When this undefined worry becomes a reality then it is reasonable for any parent to expect that they will be able to access services, which will enable them to make the right decision about the care, education and health of their child. However, we have found that this is not the case.

We have received many complaints from distraught parents whose children have been on a waiting list for years to access an assessment of need for their child. Many have found that once their child is assessed, they struggle to get any or all of the services recommended to help their child talk, move, learn and grow.

We decided to prepare and publish this report to offer an insight into the extent to which children's rights are being respected in the disability sector in Ireland. Every child with a disability in Ireland has the right, under the United Nations Convention on the Rights of the Child (UNCRC) to the highest level of health and education so as to fulfil their potential as human beings. As Ombudsman for Children, I have a statutory duty to promote the rights and welfare of children, including children with disabilities. This report raises huge concerns about the serious and ongoing violations of the rights of children with disabilities in these circumstances.

Although this report has a specific focus, we have engaged in a broad analysis of children's rights in the disability context. It is clear that the international children's rights framework offers significant guidance to the Government on the general and specific measures that it must adopt to ensure that all children's rights are respected, protected and fulfilled in respect of all children living in Ireland. We hope that this report highlights the importance of applying this framework to all Government and/or State decisions affecting children, including children with disabilities.

In particular, the task of incorporating the UNCRC fully into domestic law, which the UNCRC Committee has urged the State to implement 'as a matter of priority', remains an unfinished project, and one which I recommend that this Government complete.[1]

Incorporation would make it unlawful for public authorities to act incompatibly with the incorporated UNCRC requirements, giving children, young people and their representatives the power to go to court to enforce their rights. To paraphrase the Deputy First Minister of Scotland, John Swinney, who has sponsored a similar bill in that jurisdiction, this would have the effect of building 'children's rights into the fabric of decision making' in Ireland.[2]

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[1] "See further Joint Committee on Children and Youth Affairs, Opening Statement by the Ombudsman for Children, Dr Niall Muldoon, Wednesday, 20 November 2019

[2] Scotland is set to become the first country in the UK to directly incorporate the UN Convention on the Rights of the Child (UNCRC) into domestic law (https://www.gov.scot/news/un-convention-on-the-rights-of-the-child)

Section 1 Introduction

1.1 About the Ombudsman for Children

The Ombudsman for Children's Office (OCO) is an independent statutory body established under the Ombudsman for Children Act, 2002 (2002 Act). Under the 2002 Act, the Ombudsman for Children has two core statutory functions:

- to promote the rights and welfare of children; and
- to investigate complaints made by or on behalf of a child concerning the administrative actions of public bodies, which may have had an adverse effect on the child.

The Ombudsman for Children reports directly to the Oireachtas in relation to the exercise of these statutory functions.

1.2 Rationale for this Report

Between 2014 and 2016, the OCO received 34 complaints from parents regarding their child's access to a statutory Assessment of Need (AON). Between 2017 and 2019, the number of complaints received on this issue increased to 95. Parents related their concerns about the potential adverse effect of a delay in access to an AON on their child's development.

Some parents told us that their child had waited a number of years to access an AON via early intervention services (for children aged 0-5 years), however, their child had aged out while they were on this waiting list. Their child was then placed at the bottom of a new AON waiting list for school-aged children. This further prolonged their child's delay in access to an assessment of their needs.

Conscious of the need for early intervention in respect of children with disabilities, the OCO engaged with the HSE and other stakeholders in order to gain a full understanding of this issue.

As a result of this engagement, we concluded that the primary cause of the delay in access to AONs related to an insufficiency of resources allocated to meet the demand for AONs in particular HSE areas.

Since the allocation of resources is outside of the OCO's statutory complaints remit, we could not proceed to an investigation of these complaints. However, we remain very concerned about the potential adverse effect on children as a consequence of these delays.

1.3 Purpose of this Report

Under Section 7 of the 2002 Act, the Ombudsman for Children has a statutory duty to promote the rights and welfare of children.[3]

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[3] See also UNCRC General comment No. 2 (2002): The role of independent national human rights institutions in the promotion and protection of the rights of the child; UNCRC General Comment No. 15 (2013) on the right of the child

A key objective of the OCO's Strategic Plan 2019 - 2021 is to influence positive change for children, and to work accordingly towards the progressive realisation of the rights of vulnerable groups of children, including those with disabilities.

Correspondingly, we have produced this report in order to:

- raise awareness of the negative impact on children of difficulties arising in relation to an assessment of their needs; and
- highlight how these difficulties are presenting barriers to children's enjoyment of their rights and, therefore, constitute a children's rights issue.

This report sets out the challenges experienced by children who may have a disability and require an assessment of their needs, and proposes actions that we believe should be taken to address these challenges in a child-centred, rights-based manner.

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to the enjoyment of the highest attainable standard of health (art. 24), Para. 103

Section 2 What is an Assessment of Need?

2.1 In Principle

Framework

In September 2004, the Government launched the National Disability Strategy (NDS) with the overall aim of supporting the equal participation of people with disabilities in society.[4] At that time, there was a lack of uniformity in the provision of disability services nationally. Inconsistent approaches had developed based on geographical location, the type of service (statutory or non-statutory), and the type of disability.[5] It was envisioned that the NDS would lead to an equitable reconfiguration of disability services provided by the then health boards (now the HSE) and a number of voluntary/non-statutory bodies.

The Disability Act, 2005 (2005 Act) and its counterpart, the Education for Persons with Special Education Needs Act, 2004 (EPSEN Act) were key elements of the NDS.

The 2005 Act provided for an AON in order to determine the health or educational services required by a person with a disability. It defined the AON mechanism and its scope.

The EPSEN Act provided for an assessment of special educational needs so that further provision could be made for a child with such needs to be educated in an inclusive environment.[6]

By December 2007, the 2005 Act had commenced in full in relation to persons under 5 years of age. Sections 3 - 13 of the EPSEN Act, which concern the assessment of special educational needs in furtherance of a child's educational plan, have not been commenced. This is significant because the 2005 Act and the EPSEN Act were drafted to work in concert with one another.[7]

Definition of AON

Under the 2005 Act, the AON is an assessment undertaken or arranged by the HSE to determine the health or educational services required by a person with a disability.[8]

Rather than an assessment of the needs of the child or young person, it is an assessment of the need for services for that child or young person.

'Disability' is defined 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

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[4] Towards 2016 Strategic Document, National Disability Strategy, Vision, Mission & Strategic objectives (Section 33.2, page 66), April 2009

[5] National Disability Authority, Children's Disability Services in Ireland (2015) at p. 9

[6] Section 2 of the EPSEN Act

[7] Towards 2016 Strategic Document, National Disability Strategy, Vision, Mission & Strategic objectives (Section 33.2, page 66), April 2009

[8] Section 7 of the 2005 Act. However, in CM (A Minor) v. HSE [2020] IEHC 406 Barr J held that the sole statutory referral pathway for the assessment of children's education needs is in fact provided for under s. 8 (9) of the 2005 Act, not s. 7 of the same (para. 105).

impairment.[9] With its emphasis on productivity and participation, this definition is adult-centred rather than child-centred.

Eligibility

A young person aged 16 or 17 years can apply for their own AON,[10] otherwise an application may be made by a parent, legal guardian or personal advocate (the applicant) on behalf of a child.[11] In order to be assessed, the child must have been born after the 1st June 2002.[12] Since June 2020, all children are eligible for assessment.

Acceptance

The HSE must acknowledge receipt of the AON application within 14 days and specify a date, as soon as possible, on which the AON will commence.[13] The AON must be commenced within three months of the date of application and must be completed without undue delay.[14] It must be carried out in accordance with the standards determined by HIQA.[15] Significantly, the AON must be carried out without regard to the cost of, or the capacity to provide, any service identified by the AON to meet the needs of the child concerned.[16]

Procedure

An independent Assessment Officer conducts and prepares a report with the results of the AON. The Assessment Report sets out his/her findings with respect to whether the child has a disability and, where applicable: (i) a statement of the nature and extent of the disability; (ii) a statement of the health and education needs (if any) occasioned to the child by the disability; (iii) a statement of the services considered appropriate to meet the needs of the child and the period of time ideally required by the Assessment Officer for the provision of those services and the order of such provision; and (iv) a statement of the period within which review of the AON should be carried out.[17]

Special Educational Needs

It was envisaged that where the AON identified the need for the provision of an education service to the child, the Assessment Officer would refer the matter (1) to the principal of the child's school and the principal would take such measures as are practicable to meet the educational needs of the student concerned, or (2) for a special educational needs assessment.[18] However, (2) is not an option since the relevant sections of the EPSEN Act have not been commenced.[19]

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[9] Sections 2 & 7(2) of the 2005 Act

[10] Section 23 of the Non-Fatal Offences against the Person Act 1997

[11] Section 9(1) of the 2005 Act

[12] Part 2 'Assessment of Need, Service Statements and Redress' of the 2005 Act commenced on the 1st June 2007. It was initially envisaged that Part 2 would only apply to children under five years, however, the case of H.S.E. v. Dykes [2009] IEHC 540 expanded the class of persons to all children born after the 1st June 2002.

[13] Regulations 6 & 9 of the Disability (Assessment of Needs, Service Statements and Redress) Regulations 2007 ('2007 Regulations')

[14] Section 9(5) of the 2005 Act

[15] Regulations 15 & 16 of the 2007 Regulations; the HIQA Standards for the Assessment of Need, May 2007

[16] Sections 8(5) & 10 of the 2005 Act

[17] Section 8(5) of the 2005 Act

[18] Section 8(9) of the 2005 Act

[19] Sections 3 and 4 of the EPSEN Act, concerning special educational needs assessment; Towards 2016 Strategic Document, National Disability Strategy, Vision, Mission & Strategic objectives (Section 33.2, page 66), April 2009. The NCSE informed the OCO that, in the case of child not yet in school, the NCSE arranges for this assessment.

Service Statement

Once it has been determined that the child has a disability and the provision of health services are appropriate, the Assessment Report is sent to a Liaison Officer who prepares a Service Statement.[20] This Statement must be completed within one month.[21]

The Service Statement must specify (a) the health services which will be provided to the child; (b) the location(s) where the health service will be provided; (c) the timeframe for the provision of the health service; (d) the date from which the Service Statement will take effect; (e) the date for review of the provision of services specified in the Service Statement; and (f) any other information that the Liaison Officer considers appropriate.[22]

The completed Service Statement must be furnished to the applicant, the HSE, and, if appropriate, the NCSE and the head of the education service provider concerned, without undue delay.[23] The Liaison Officer must invite the applicant to meet to review the provision of services specified in the Service Statement and must arrange for the delivery of the services at the time and manner set out.[24] The Service Statement must be reviewed no later than 12 months after it was drawn up, last reviewed or amended.[25]

Review

An applicant can make a complaint to the HSE regarding (a) a determination that the child does not have a disability; (b) the fact that the AON was not commenced within three months or was not completed without undue delay; (c) the fact that the AON was not conducted in a manner that conforms to the standards determined by the standard's body; (d) the contents of the Service Statement; or (e) the fact that the HSE or the education service provider failed to provide, or to provide in full, a service specified in the Service Statement. The HSE must refer the complaint to a Complaints Officer within 10 days. If the Complaints Officer is of the opinion that informal resolution is unsuitable, s/he will investigate the complaint and prepare a report setting out his or her findings and recommendations.[26]

A complainant may, within six weeks of receipt of the Complaints Officer's report, appeal a finding or recommendation of the Complaints Officer, or the non-implementation of a recommendation of the Complaints Officer by the HSE or education service provider, to the Disability Appeals Officer at the Department of Health.[27] A complainant or Disability Appeals Officer may also apply to the Circuit Court for an enforcement order three months after the non-implementation of a recommendation of the Complaints Officer or Disability Appeals Officer.[28] An appeal to the High Court may only be made on a point of law.[29]

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[20] Section 11(2) of the 2005 Act

[21] Regulation 19 of the 2007 Regulations

[22] Regulation 18 of the 2007 Regulations

[23] Section 11(8) of the 2005 Act

[24] Sections 11(11) & (12) of the 2005 Act

[25] Regulation 22 of the 2007 Regulations

[26] Section 15 of the 2005 Act

[27] Section 18 of the 2005 Act

[28] Section 22 of the 2005 Act. According to the HSE, to date, the Disability Appeals Officer has never applied to the Circuit Court for an enforcement order.

[29] Section 20 of the 2005 Act

2.2 In Practice

According to the HSE, the AON was designed to determine whether or not a child has a disability, and the nature and extent of that disability. The HSE informed the OCO that the AON should result in an Assessment Report that lists the services a child with a disability requires, and a Service Statement that lists the services, which the State can provide.

In practice, an insufficiency of resources allocated to meet the demand for AONs has hampered the effectiveness of the 2005 Act mechanism. This is apparent in (i) the Government's decision to defer the enactment of relevant sections of the EPSEN Act, (ii) the low volume of applications processed, (iii) the lack of consistency across local HSE Community Healthcare Organisations (CHOs),[30] and (iv) the stagnation in the review process.

Furthermore, Government policy has evolved in this area and many stakeholders have questioned whether the 2005 Act mechanism is still fit for purpose.

(i) The EPSEN Act

Under the NDS, it was envisaged that the 2005 Act would cover assessments for health needs and EPSEN would cover assessments for special educational needs. Furthermore, the OCO was advised that the original legislative intent was for the 2005 Act to operate in respect of children up to school going age (0-5 years of age) and that the EPSEN Act would take over in relation to special educational provision once a child reached school starting age.

In 2008, due to financial constraints, the Government deferred the enactment of the relevant sections of the EPSEN Act.[31] These sections have never been brought into effect.[32]

While there is some evidence that such assessments are carried out on an ad hoc basis, using hours assigned by the National Educational Psychological Service (NEPS) to the particular school, there is no statutory assessment scheme for special educational needs in operation, no timelines within which such an assessment must be carried out, and no mechanism to complain about the lack of such an assessment.[33]

In the absence of a procedure under the EPSEN Act, students who require an assessment of their special educational needs are applying for an AON under the 2005 Act. This places further pressure on the 2005 Act mechanism.[34]

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[30] A Community Healthcare Organisation operates through an average of 10 primary care networks. The population of each CHO ranges from approximately 350,000 – 700,000 people.

[31] Department of Health and Children, Sectoral Plan under the Disability Act 2005: Progress Report Year 3 Review (2009) at 2. The Department of Education was not one of the six departments that had to propose a sectoral plan when the 2005 Act was introduced. These sectoral plans were maps for how each department would implement the 2005 Act, specific to their functions.

[32] The NCSE contends that, since 2008, the Government has continued to prioritise investing in educational resources for schools to support students with special educational needs. They state that spending on school special educational supports has increased from €900m in 2008 (NCSE Policy Advice Paper no 4: May 2013) to €1.9bn (per Minister for Education and Skills in a reply to PQ numbers 224, 225, 226, 228 & 229 on 17.12.2019), and that in 2017, the Minister of Education and Skills removed the requirement for a student to have a formal diagnosis before being able to access resource teaching support.

[33] NEPS informed the OCO that it also provides significant support through its Support and Development work to build school capacity to support the wellbeing, and academic, social and emotional development of all students, including those with more complex needs. They state that a formal diagnosis is no longer needed within the educational system to access Special Education Teacher support, access to the Reasonable Accommodations in Certificate Examinations (RACE) scheme or access to an Irish exemption. They further state that the system has moved to a needs-based system rather than a diagnosis driven system and is continuing to move in that direction in relation to the provision of Special Needs Assistant support, with the emphasis now on inclusion and participation.

[34] Inclusion Ireland, Submission to the Oireachtas Joint Committee on Justice, Defence and Equality on the Operation

(ii) Volume of Applications

The HSE informed the OCO that there has been a significant increase in the number of applications for AONs over the last 10 years, exceeding the capacity of services to meet this demand. Indeed, the number of applications for AONs has risen steadily over the past 11 years, from 1138 applications in 2007[35] to 5060 in 2018.[36] The statutory timeframes for the completion of AONs are also routinely not met by the HSE. In 2018, the number of assessments completed on time was 8.8%. The HSE National Service Plans for 2019 and 2020 gave a projected outturn of 9% of AONs completed within the timeframes provided for in the 2007 Regulations.[37]

(ii) Lack of Consistency

In line with an increase in the volume of applications, disparities have emerged between CHOs with regard to the number of applications received, Assessment Reports completed, and Service Statements finalised. This reflects a lack of cohesion and consistency in approach to AONs across, and within, CHOs.[38]

The 2005 Act provides that each AON should be carried out in line with certain standards and a complaint may be brought if an assessment is not carried out in line with such standards.[39]

In May 2007, the Standards for Assessment of Need were adopted by the Board of the Interim HIQA.[40] According to stakeholders, these standards are both outdated and too general to be utilised in practice.[41] Indeed, HIQA informed the OCO that the Standards needed to be updated in line with its current methodology. According to HIQA, the current standards are factually inaccurate, but cannot be retired without new standards being developed to replace them.

HIQA informed the OCO that a new set of national standards are required to create an overarching framework of high level principles through which actual care can be consistently measured against optimal care. It is understood that a proposal for an update of the 2007 Standards for the Assessment of Need for Persons with Disabilities is due to be considered by HIQA's Programme Advisory Group in September 2020. According to HIQA, any update to the National Standards for the Assessment of Need would be undertaken in the context of work in progress to develop a set of Overarching National Standards for the Care and Support of Children Using Health and Social Care Services. HIQA informed the OCO that while revised National Standards will bring clarity and standardisation to the assessment process, they would not infer an entitlement to the services identified as part of the assessment process or address resource issues within the individual CHO areas.[42]

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of the Disability Act 2005 (2015) at 7 and National Disability Authority, Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005 (2011) at p. 79

[35] Dáil Éireann Debate: Disability Support Services Provision: Questions, Vol. 984 No. 5 (2 July 2019)

[36] HSE Quarterly Reports from 2018

[37] Health Service Executive, National Service Plan 2019 at p. 129 and National Service Plan 2020 at p.126

[38] Joint Oireachtas Committee on Health, New Operating Procedures for Assessment of Need (Jan 2019) at 9

[39] Joint Oireachtas Committee on Health, New Operating Procedures for Assessment of Need (Jan 2019) at 9

[40] Section 8(1)(m) of the Health Act 2007

[41] National Disability Authority, Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005 (2011) at p. 66. For example, these standards say that the 2005 Act will apply to adults no later than 2011 however, as is now apparent, that will not happen until June 2020. They say that assessments of need will be available under EPSEN by 2010 but there is currently no apparent intention to bring EPSEN into effect.

[42] Health Service Executive, Standard Operating Procedure V2 (2019) at para. 7.2.6.k, 7.2.8.a & 7.2.9.j

Similarly, in order to create a more uniform approach to AONs, the HSE has proposed a new Standard Operating Procedure (SOP). The SOP provides a standardised procedure for application forms, Assessment Reports, Service Statements, consent forms and to the overall management of the AON process. It is the responsibility of the National Disability Children and Families Team (Disability Team) to review this procedure on a regular basis and to update it as required, having regard to the views and submissions of CHO areas.

An Assessment Officer currently has a total of six months to complete the AON and write up the Assessment Report. Under the new SOP, the initial screening must be done within three months of receiving the application. If the Assessment Officer finds that the child has a disability, the child will be referred to the Children's Network Disability Service for a 'preliminary team assessment'. If the Assessment Officer is uncertain as to whether the child has a disability, the application will be discussed at the Integrated Children's Services Forum. In exceptional circumstances, the Assessment Officer may agree to meet with the applicant.[43]

If the Assessment Officer determines that the child does not have a disability, their caregivers should be advised, in an accompanying letter, on how to access services to meet the child's needs. However, the Assessment Report itself must not identify any particular health or education needs.[44]

A number of practitioners and parents have raised concerns about the new SOP, contesting that the initial screening would push back a child's assessment by three months, and that the assessment itself will be less thorough, given the 90-minute time restriction placed on clinicians. The proposed system does, however, allow for a full diagnostic assessment, which would provide the child with a pathway for access to services within the system's current configuration.

The new SOP was subject to a review by the Joint Oireachtas Committee on Health in June 2018.[45] In its report, the Joint Oireachtas Committee on Health noted that 'early diagnosis, early action and early treatment are key to positive outcomes' and that it was essential that assessments were provided in the 'golden window of opportunity', a critical period of a child's development during pre-school and early-school years.

Furthermore, it commented that a failure to provide services at this stage would have a deteriorating effect on the child.

It concluded that the current AON process does not effectively provide for early intervention.[46] In its report, the Joint Oireachtas Committee on Health recommended that:

1. The Committee, while acknowledging the benefits of early intervention, recommends that the Government allocates sufficient resources to support this programme. The Committee also acknowledges the societal and financial benefits of early intervention as well as the potential positive developmental outcomes for children with additional needs.
2. The Committee recommends that HSE policy reflects the importance

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[43] Ibid at para. 7.2.4.e

[44] Ibid at para. 7.5.1.b

[45] Joint Oireachtas Committee on Health, New Standard Operating Procedure for Assessment of Need under the Disability Act 2005: Discussion (27 June 2018)

[46] Joint Committee on Health, New Operating Procedures for Assessment of Need (January 2019) at 1, 2, 11, 16 & 17

of early intervention. The Committee believes that early intervention is especially valuable to the Assessment of Need process and as such, its procedures and its allocation of resources should be supportive of early intervention. Currently the AON process does not effectively provide for early intervention.

3. The Committee recommends that further consideration be given to the drafting of the Standard Additional Information Form.[47] The Committee notes the concerns of stakeholders regarding the ability of such a process to adequately determine whether or not a child has a disability. The Committee also notes the concerns of parents as to the complexity of the form. The Committee recommends that the HSE consult with front-line therapists and parents to discuss the matter further.

4. The Committee recommends that the new Standard Operating Procedure is not brought into use before consultation with front-line therapists and parents. Such a consultation process should involve discussions regarding specific concerns of stakeholders as well as informing all parties of the requirements and specification for the new SOP. The Committee welcomes the HSE's commitment to engage with assessment officers and instruct that the current AON process should be in use. However, the Committee is concerned that, at present, communication between the HSE and assessment officers is not effective.

5. The Committee recommends that the HSE give further consideration to the testimony of stakeholders and their concerns regarding the Preliminary Team Assessment. The Committee has concerns that the proposed Assessment does not prioritise the child's best interests and may further delay access to services. The Committee recommends further consultation between the HSE, parent advocate groups and the therapists.

6. The Committee recommends continuous discussions between the HSE, parents and front-line therapists with regard to the Assessment of Need process. The Committee especially believes the experience and insight of therapists and parents is valuable and should be utilised in the drafting of the AON process. The Committee believes that a consistent approach to the AON process is vital but recommends that the outcome of the process must be the provision of early diagnosis, early intervention and early treatment.

7. The Committee recommends the establishment of a central database of Assessment of Need data which is accessible to all therapists, clinicians and administrators involved in AON. Such a database should allow access to information on a real-time basis and assist in expediting the Assessment of Need process.

8. The Committee has grave concerns regarding the current waiting lists on the Assessment of Need process. The Committee is of the view that in order to address these waiting lists, the following must be achieved

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[47] According to the HSE, this form was reviewed by an interdisciplinary group of clinicians in early 2019.

without delay:
i) reconfiguration of CHOs;
(ii) recruitment of additional therapists for Disability Teams; and
(iii) provision of adequate resources to Disability Teams.

9. The Committee recommends that the recruitment process for hiring staff is reformed to ensure a quicker, more efficient system.

10. The Committee recommends the employment of a sufficient number of therapists to manage the increasing number of applications for Assessment of Need in a timely manner.

11. The Committee recommends that an audit is undertaken to ascertain data regarding the Assessment of Need process. Such data should include the total number of children with disabilities, the total number of staff in each CHO and the additional requirements for each CHO.[48]

Following a consultation with stakeholders,[49] the HSE informed the OCO that the new SOP would be implemented from January 2020.[50] The new SOP is due to be reviewed by an independent Chair after 12 months (January 2021).

In a Joint Statement, the Psychological Society of Ireland, the Association of Occupational Therapists of Ireland, and the Irish Association of Speech & Language Therapists endorsed the recommendations of the Joint Oireachtas Committee on Health, and called upon the HSE to pause the implementation of the new SOP, revisit the recommendations of the Joint Oireachtas Committee on Health and commit to meaningful engagement with professional bodies and service user representatives.[51]

(iv) The Review Process

For years, the complaints system operated as a further delay in the provision of AON services. According to the HSE's Annual Reports and Financial Statements, there were 4,040 AON complaints recorded between 2011 and 2018. Despite the volume of complaints, there was only one Complaints Officer operating in the country during this time and complainants needed to wait six to eight months for a recommendation.[52]

In 2018 proceedings, the High Court considered the complaints process, as set out in the 2005 Act. While it did not find anything inherently wrong with the process, the Court determined that it was unreasonable for the complaints process to subject the complainant to further delay in access to an AON for their child, especially given the need for early intervention.[53]

Of the determinations issued in 2017, 97.6% of appeals were upheld. Of those determined in 2018, 100% were upheld.[54] This created an inequity in the complaints process, whereby children with caregivers who have the resources to make a complaint or bring a legal

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[48] Ibid at p. 6-7

[49] According to the HSE, a workshop with all stakeholders was held in September 2018, and an independent clinical opinion was provided by Professor Malcolm MacLachlan.

[50] A National Coordination Group for the Disability Act is to be established in parallel to this

[51] https://www.aoti.ie/news/Joint-Statement-Issued-by-AOTI-PSI-and-IASLT

[52] .F. v H.S.E.; K.K. v H.S.E. [2018] I.E.H.C. 294

[53] Ibid at para. 73, 80 & 83

[54] Office of the Disability Appeals Officer, Annual Report of the Disability Appeals Officer 2017 at p.11 & Annual Report of the Disability Appeals Officer 2018 at p. 8

challenge are prioritised, when other children, who may not have the resources, are not.

The HSE informed the OCO that it has made significant progress in addressing delays in the AON complaints process, and that these complaints are now processed in a timely manner.

(v) Evolution of Policy

Successive iterations of the NDS have set out an approach for the progressive realisation of the aims of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), working to resolve many social and economic issues identified in the Convention. These policies include Progressing Disability Services for Children and Young People 2010 (PDSCYP); the National Healthcare Charter for Children 2013; the National Access Policy 2016; and Better Outcomes Brighter Futures: The National Policy Framework for Children and Young People 2014 - 2020.

Significantly, the aims and objectives of the PDSCYP, which are echoed in the National Access Policy 2016, are as follows:

- a clear pathway to services for all children according to need;
- effective teams working in partnership with parents and service users;
- resources used to the greatest benefit for all children and families; and
- partnership between health and education to support children to achieve their potential.

The principles underpinning the National Access Policy 2016 are as follows:

- services exist to support children, young people and their families;
- access to services is equitable;
- access to services is needs led rather than diagnosis led;
- children are seen at the level of service nearest their home, which best addresses their needs;
- no child is left without timely access to an appropriate service to meet their needs;
- parents know their child better than anyone else and should be treated by professionals as equal partners given the expertise they have in the care of their child;
- a family-centred approach is a continuing process that begins at the moment of initial contact with families; and
- a child's need for services does not exist in isolation from their other needs and from the needs of their family.[55]

Since the 2005 Act came into force, national policy and programmes have moved towards the progressive realisation of children's health and development rights, and a needs led, rather than diagnosis led, service model. As such, the 2005 Act mechanism as drafted is at odds with the principles that now underscore national policy in this area.

In the new Programme for Government's 'Mission: A New Social Contract', the current Government commits to empower and give those with a disability the ability to choose

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[55] National Access Policy 2016 at p. 7

the supports that most meet their needs. Reflecting this, it states that the Government will:

- Prioritise early diagnosis interventions and access to services;
- Improve and change services through better implementation and collaboration;
- Strengthen rights through the UN Convention on the Rights of People with a Disability (UNCRPD);
- Raise awareness of the lived experience of people with disabilities;
- Ensure that the most effective interventions are provided for each individual, to guarantee the best outcomes;
- Seek to reduce the waiting times for assessment of need under the Disability Act 2005, through the full-year provision of additional therapy posts;
- Fully implement the new standard operating procedure for assessment of needs for all applications;
- Fully complete the establishment of the Progressing Disability Services for Children and Young People (0- 18 years) Network Teams.
- Integrate access to mental health supports as part of disability service provision;
- Resource the National Disability Inclusion Strategy, with an emphasis on close collaboration between state agencies and civil society;
- Continue with the successful decongregation programme and complete a further move of more people with disabilities from congregated settings to homes in the community, with the necessary supports.[56]

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[56] Page 78, Programme for Government, June 2020

Section 3 Children's Perspectives

Early childhood is a critical period for realising children's rights. Children's earliest years are the foundation for their physical and mental health, emotional security, cultural and personal identity, and developing competencies.[57]

These case studies emphasise that, where a disability is suspected, it is essential that children have access to services for the early identification, early intervention and early treatment that will allow them to reach their full potential.

3.1 Andrew's Story

Andrew has suspected Autism Spectrum Disorder (ASD). In March 2018, when Andrew was eighteen months old, his mother applied for an AON on his behalf. In August 2018, Andrew was seen by an Assessment Officer who identified a need for occupational therapy, speech & language therapy (SLT), as well as a psychological assessment.

The HSE informed Andrew's mother that her son would need to wait approximately one year to access a psychological assessment. She made a complaint to the HSE with respect to this delay. She was told that her complaint would not be heard for approximately seven months. As a result, she made a complaint to the OCO regarding her son's delayed access to a psychological assessment, and the HSE's delay in addressing her complaint.

A psychological report is a requirement for entry to an ASD specialist pre-school. Andrew's mother informed us that a failure to complete Andrew's psychological assessment in advance of his third birthday would impede his chances of being enrolled in a pre-school appropriate to his needs, which could in turn have an overall adverse effect on his long-term education.

3.2 Lucy's Story

Lucy is non-verbal and has a diagnosis of ASD combined with Mild General Learning Difficulties. She goes to a school with an ASD class and communicates using a limited amount of sign language. Her mother informed us that, although Lucy has a communication device, neither Lucy nor her family know how to use it effectively. She said that Lucy has poor balance and requires close supervision when going up and down stairs, as well as assistance with her self-care.

In 2015, when Lucy was six years old, she had an AON. The Services Statement identified a need for SLT and physiotherapy, to help her build muscle tone. It recommended that Lucy be seen by a multidisciplinary team for intervention, as soon as possible. Lucy was placed on a waiting list for clinical services.

In 2018, Lucy's mother was informed by the HSE that Lucy would need to wait a further two years for clinical services. She was told that her CHO did not operate a referrals prioritisation system. Lucy was also referred by her school to the HSE Early Intervention Team, but that referral was declined because she was already waitlisted for another service.

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[57] UNCRC General Comment No. 7 (2005) Implementing child rights in early childhood at paragraph 6

Lucy's mother told us that she believes that the absence of clinical services is having a critical, adverse impact on Lucy's development, especially her speech. Lucy, who is now 11 years of age, is still not receiving any of the clinical services assessed to meet her needs as a six-year-old.

3.3 Michael's Story

Michael is non-verbal and has suspected ASD. When he was two years old, his mother wrote to their local CHO requesting an AON. Michael was referred to the HSE Early Intervention Team and they referred him on to one of their voluntary providers for an ASD assessment. His mother was informed that there would be a significant delay in accessing an ASD assessment, but that she could make a complaint to the Complaints Officer about this.

After 10 months, Michael's mother was informed that her complaint was upheld. The Complaint's Officer recommended that the HSE provide Michael with his Assessment Report within 10 weeks and his Service Statement four weeks later. When this did not happen, Michael's mother was informed by the Complaints Officer that she could go to the Circuit Court to force the HSE to implement their recommendations. By the time she contacted us, Michael had been waiting 19 months for his AON.[58]

Michael's mother is worried that without an AON, he will regress developmentally, and will not be able to access a special school.

3.4 Sarah's Story

Sarah has been privately assessed as having ASD. She also has sensory issues, is unable to wash or dress herself, and her co-ordination is poor. When she was four years old, her mother applied to her local HSE Early Intervention Team for an AON. She was informed that Sarah would have to wait at least 27 months for an AON and that, when she turned five, she would be transferred to the School Aged Team waiting list. Sarah would not receive any priority on that list, despite 'aging out' of the Early Intervention Team waiting list.

Sarah's mother complained to the HSE regarding the delay. Her complaint was upheld but Sarah has still not received an AON.

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[58] The average current waiting time for AON is 19 months with 5000 children waiting longer than the law permits ('Delay for special needs assessment too long – Varadkar', RTE.ie, 30th July 2020)

Section 4 A Child Rights-Based Approach

4.1 Relevant Children's Rights Standards

Ireland is a dualist state. Individuals may only plead human rights, which have been incorporated into Irish law, before the national courts i.e. rights protected under the Irish Constitution, the European Convention of Human Rights Act 2003 (2003 Act), and the European Union Charter of Fundamental Rights (EU Charter), where European Union (EU) law is applicable.[59]

Where an international human rights treaty has been ratified, but has not been incorporated into Irish law, the State is still bound by these standards in international law. Furthermore, national courts have attached a form of persuasive authority to these human rights instruments.[60]

4.1.1 Irish Constitution

Article 42A.1 of the Irish Constitution recognises and affirms the natural and imprescriptible rights of all children, and the State as the body responsible for the vindication of those rights.

Article 42.4 of the Irish Constitution states that 'The State shall provide for free primary education and 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 with due regard, however, for the rights of parents, especially in the matter of religious and moral formation.'

4.1.2 European Union Charter of Fundamental Rights

The rights of the child, and the right to healthcare, are further enshrined in the EU Charter. The provisions of the EU Charter are addressed to the Irish State when it is implementing EU law.[61]

4.1.3 European Convention of Human Rights Act 2003

Ireland ratified the European Convention on Human Rights (ECHR), a Council of Europe treaty which guarantees fundamental civil and political rights, in 1953. It was incorporated into Irish law by the 2003 Act. Section 4 of the 2003 Act requires all organs of the State to conduct their activities in a manner that is compatible with Ireland's ECHR obligations.

Although the ECHR does not contain a direct provision relating to children's access to health care, the European Court of Human Rights has developed a practice of interpreting and applying substantive Convention rights in light of the children's

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[59] Article 29.6 of the Irish Constitution provides that 'no international agreement shall be part of the domestic law of the State save as may be provided by the Oireachtas'.

[60] Ratification attracts the rule of international law that State Party obligations must be performed in good faith in respect of the State Party's entire territory under Articles 26 and 29 of the Vienna Convention on the Law of Treaties 1969.

[61] Articles 24 & 35 of the EU Charter of Fundamental Rights

rights principles contained in the UNCRC. In particular, much of the Court's case-law establishes the importance of the 'best interests principle'.[62]

4.1.4 European Social Charter

The European Social Charter (ESC) is a Council of Europe treaty that guarantees fundamental social and economic rights. It is a counterpart to the ECHR, which is concerned with civil and political rights. The ESC provides for the right to protection of health, the right to social and medical assistance, the right of persons with disabilities to independence, social integration and participation in the life of the community, and the right of children and young persons to social, legal and economic protection.[63]

The revised ESC came into force in 1999. The European Committee of Social Rights (ESC Committee) monitors the conformity of national law and practice with the ESC through a periodic reporting mechanism. The ESC Committee's Conclusions on Ireland in 2017 found that, with respect to 'Article 11 - Right to protection of health; Paragraph 1 - Removal of the causes of ill-health; Access to health care (pages 540 – 541)':

'Given the lack of information in the report, in particular as regards waiting times and the proportion of out-of-pocket payments for healthcare, the Committee considers that it has not been established that the right of access to healthcare is guaranteed in practice [...] The Committee concludes that the situation in Ireland is not in conformity with Article 11.1 of the Charter on the ground that it has not been established that the right of access to healthcare is guaranteed in practice'.[64]

Under the ESC collective complaints mechanism, certain organisations, such as employers' organisations and trade unions, are entitled to lodge complaints of violations of the ESC with the ESC Committee.

4.1.5 International Covenant on Economic, Social and Cultural Rights

Ireland ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR) in 1989. Ireland is required to submit periodic reports to the United Nations Committee on Economic, Social and Cultural Rights (ICESCR Committee) on progress made to protect, respect and fulfil the social and economic rights enshrined in this treaty.

4.1.6 United Nations Convention on the Rights of the Child

The principal international children's rights instrument is the UNCRC, which was adopted by the General Assembly of the United Nations (UN) in 1989. It is widely considered to be the gold standard for a child rights-based approach. The UNCRC is a comprehensive document which recognises children as autonomous rights holders and sets out the obligations of the State as a duty bearer.

Although the UNCRC has not been incorporated into Irish law, Ireland ratified the UNCRC in 1992 and is subject to the treaty monitoring procedure.

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[62] U. Kilkelly, "The Best of Both Worlds for Children's Rights? Interpreting the European Convention on Human Rights in Light of the UN Convention on the Rights of the Child" (2001) 23(2) Human Rights Quarterly 308 at p. 324

[63] Articles 11, 13, 15 & 17 of the ESC

[64] European Committee of Social Rights, Conclusions 2017 IRELAND at p. 15

With respect to the rights of children with disabilities, the UNCRC Concluding observations on the combined third and fourth periodic reports of Ireland[65] stated that:

'48. In the light of its general comment No. 9 (2006) on the rights of children with disabilities, the Committee recommends that the State party:

(a) Adopt a human rights-based approach to disability and establish a comprehensive strategy for the inclusion of children with disabilities'[66]

Ireland became one of the first States to ratify the 3rd Optional Protocol to the UNCRC on a Communications Procedure in September 2014. This mechanism was designed to allow children and their representatives to bring complaints to the UN Committee on the Rights of the Child (UNCRC Committee) in respect of alleged violations of their rights under the UNCRC and its Optional Protocols.

4.1.7 United Nations Convention on the Rights of Persons with Disabilities

The CRPD was adopted by the General Assembly of the UN in 2006. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

Ireland ratified the CRPD in 2018 affirming its commitment to protect the rights of persons with disabilities. Ireland's initial State party report to the United Nations Committee on the Rights of Persons with Disabilities (CRPD Committee) was due on the 20th April 2020. In accordance with Article 35 of the CRPD, Ireland must submit a comprehensive report on measures taken to give effect to its specific obligations under the CRPD, and on the progress made in that regard, since the CRPD's entry into force. The report may indicate factors and difficulties affecting the degree of fulfilment of Ireland's obligations under the CRPD.

The Government has not yet ratified the Optional Protocol to the CRPD, which would allow persons with disabilities to make individual complaints to the CRPD Committee. The Government has stated that it will ratify the Optional Protocol in 2020, when it makes its first report to the CRPD Committee.[67]

In its Programme for Government, the Government reiterated its commitment to enshrine disability rights by finalising the legislation required following Ireland's recent ratification of the UN Convention on the Rights of People with Disabilities. It states that this legislation will:

- Double the target for employment of people with disabilities in the public service to 6%;
- Reform the Mental Health Act 2001;
- Improve protections for people with disabilities against hate crime and hate speech;
- Improve access for people with disabilities to jury service.
- Remove outdated references to 'persons of unsound mind' from the Statute Book;

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[65] Committee on the Rights of the Child, Concluding Observations on the Combined Third and Fourth Periodic Reports of Ireland (CRC/C/IRL/CO/3-4

[66] Ibid at p. 10.

[67] https://www.ihrec.ie/app/uploads/2018/09/CRPD-Explained-A-Brief-Guide-to-the-CRPD.pdf

- Commence the Assisted Decision-Making (Capacity) Act 2015 to abolish wardships;
- Develop an implementation plan to coordinate implementation of the UNCRPD;
- Implement a consultation and participation model, in line with the UNCRPD, to enable people with disabilities to participate in the policy development process;
- Ratify the Optional Protocol to the UNCRPD after the first reporting cycle.
- Work with other parties in the Oireachtas to establish a Joint Oireachtas Committee to assist in monitoring and implementing the provisions in the Convention on the Rights of People with Disabilities.[68]

4.2 Implementing a Child Rights-Based Approach

4.2.1 Children as Rights Holders

If children are to develop, progress, engage and thrive, it is incumbent upon the Irish State to see children as holders of natural and imprescriptible rights, and affirm those rights in a holistic way.[69]

The State must take all appropriate measures to ensure that children with disabilities enjoy all human rights and fundamental freedoms on an equal basis with other children. This includes the right to respect for his or her physical and mental integrity.[70]

4.2.2 Children's Rights Principles and Provisions

The following core principles and provisions should be central to all State decisions affecting children's health and development, including resource allocation and the development and implementation of policies and interventions that affect the underlying determinants of their health. The OCO considers all of these rights engaged in the context of the AON mechanism:

- ***The best interests of the child***
  In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child must be a primary consideration. It should be adjusted and defined on an individual basis, according to the specific situation of the child or children concerned, taking into consideration their personal context, situation and needs. There is a duty on the State to uphold the child's best interests with respect to the allocation of national resources for programmes and measures aimed at implementing children's rights.[71]

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[68] Page 78, Programme for Government, June 2020

[69] Article 42A.1 of the Irish Constitution recognises the child as a holder of rights and the State as the body responsible for the vindication of those rights; UNCRC General Comment No. 9 (2006) The rights of children with disabilities, Para. 33

[70] Articles 7 & 17 of the CRPD; Article 2 of the UNCRC; UNCRC General comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6), Paragraph 12; ICESCR General comment No. 5: Persons with disabilities, Para. 34

[71] Article 2 of the UNCRC; UNCRC General Comment No. 14 (2013) on the right of the child to have his or her best

- ***The right to survival and development***
  The State must ensure the survival and development of the child to the maximum extent possible. 'Development' should be interpreted 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.[72]

- ***The rights of children with disabilities***
  Children with disabilities are entitled to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. In recognition of the right of the child with a disability to special care, the State must extend such assistance as appropriate to the child's condition, subject to available resources. This assistance must be designed to ensure that the child with a disability 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

  The State is encouraged to establish an appropriate definition that guarantees the inclusion of all children with disabilities so that children with disabilities may benefit from the special protection and programmes developed for them. The State's health policies should be comprehensive and address the early identification and early intervention of disabilities as part of its health services, in order to minimise and prevent further disabilities.[73]

- ***The right to non-discrimination***
  The right to non-discrimination requires the State to take active steps to identify individual children and groups of children, who may require special measures for the recognition and realisation of their rights. The UNCRC Committee highlights the need for data collection to be disaggregated to enable discrimination or potential discrimination to be identified.[74]

- ***The right to health***
  Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity. Children have a right to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and the rehabilitation of health. The State must strive to ensure that no child is deprived of his or her right of access to health care services.

  The State must take appropriate measures to ensure the provision of

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interests taken as a primary consideration (art. 3, para. 1) Paragraph 15 & 32

[72] Article 6 of the UNCRC; UNCRC General comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6), Paragraph 12; Article 12 of ICESCR

[73] Article 23 of the UNCRC; UNCRC General Comment No. 9 (2006) The rights of children with disabilities, Paragraph 19, 51 & 56; Article 25 of the CRPD

[74] Articles 7 & 17 of the CRPD; Article 2 of the UNCRC; UNCRC General comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6), Paragraph 12; ICESCR General comment No. 5: Persons with disabilities, Para. 34

the necessary medical assistance and primary, secondary and tertiary health care to all children. The State should provide health services that are sensitive to the particular needs and rights of all children, paying attention to the (a) availability, (b) accessibility, (c) acceptability, and (d) quality of services in their decisions regarding budget allocation and spending.

The State is encouraged to put in place a functional and accessible complaints mechanisms for children to seek and obtain reparations when their right to health is violated or at risk.[75]

- ***The right to education***
  The State agrees that the education of the child should be directed to the development of the child's personality, talents and mental and physical abilities to their fullest potential i.e. the holistic development of the full potential of the child. Education must be child-centred, child-friendly, empowering, and free from overt or hidden discriminatory practices, which destroy the capacity of the child to benefit from educational opportunities.

  Children with disabilities should be provided with reasonable accommodation, and effective individualised support measures in educational environments that maximise academic and social development, consistent with the goal of full inclusion. The denial of reasonable accommodation constitutes discrimination and the duty to provide reasonable accommodation is immediately applicable and not subject to progressive realisation.[76]

- ***The right to be heard***
  The State must assure that where a child is capable of forming his or her own views, they may express those views freely in all matters affecting them, and that their views are given due weight in accordance with their age and maturity. They may be represented through a representative or an appropriate body, where necessary.[77]

4.2.3 State Responsibility for Implementing Children's Rights

The concept of 'progressive realisation' describes the State's obligation to undertake all appropriate legislative, administrative, and other measures to the maximum extent of their available resources for the implementation of a child's economic, social and cultural rights. Even where the available resources are demonstrably inadequate, the State is still obliged to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances. This reflects a recognition that the realisation of these rights can be hampered by a lack of resources and can be achieved only over a period of time.

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[75] The Preamble to the Constitution of the World Health Organisation (1947); Article 24 of the UNCRC; UNCRC General comment No. 4 (2003) - Adolescent health and development in the context of the Convention on the Rights of the Child, Paragraph 41; UNCRC General Comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (art. 24), Paragraphs 4, 25, 104, 112-116 & 119; ICESCR General Comment No. 14 (2000) The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights), Para. 22-24

[76] Articles 2, 28 & 29 of the UNCRC; UNCRC General comment No. 1 (2001) Article 29(1) The Aims of Education, Paragraphs 1, 2 & 10; Articles 24 of the CRPD; CRPD General comment No. 4 (2016) on the right to inclusive education, Para. 31

[77] Article 12 of the UNCRC

Whatever their economic circumstances, States are required to undertake all possible measures towards the realisation of the rights of the child, paying special attention to the most disadvantaged groups.[78]

4.2.4 Measures to Implement Children's Rights

The enjoyment of economic, social and cultural rights is inextricably intertwined with the enjoyment of civil and political rights. The interdependence and indivisibility of all human rights is reflected throughout the UNCRC, with many articles containing elements which constitute civil/political rights.[79]

For this reason, the UNCRC Committee believes that economic, social and cultural rights, as well as civil and political rights, should be regarded as justiciable. It is, therefore, essential that domestic law sets out entitlements in sufficient detail to enable remedies for non-compliance to be effective.[80]

The State must see its role as fulfilling clear legal obligations to each and every child. The development of a children's rights perspective throughout Government, parliament and the judiciary is required for effective implementation of a child-rights based approach.

Significantly, the general measures of implementation of the UNCRC require:

- Every legislative, administrative and judicial body or institution to apply the best interests principle by systematically considering how children's rights and interests are or will be affected by their decisions and actions;
- The State to undertake all appropriate legislative, administrative, and other measures for the implementation of children's rights;
- The State to undertake visible cross-sectoral coordination to recognise and realise children's rights across Government, between different levels of government, and between Government and civil society. This may take the form of inter-ministerial and interdepartmental committees for children with high-level authority;
- With regard to economic, social and cultural rights, the State to undertake such measures to the maximum extent of their available resources;
- Effective remedies to be available to redress violations, in order for rights to have meaning. States need to give particular attention to ensuring that there are effective, child-sensitive procedures available to children and their representatives;
- The collection of sufficient and reliable data on children, disaggregated to enable the identification of disparities in the realisation of rights; and
- Raising awareness about the rights of the child, which should involve all sectors of society, including children and young people.[81]

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[78] Article 4 of the UNCRC; UNCRC General comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6), Paragraphs 8, 11, 24 & 48; UNCRC General Comment No. 19 (2016) on public budgeting for the realization of children's rights (art. 4), Para. 1; Article 4(2) of the CRPD; Article 2(1) of the ICESCR

[79] Articles 2, 3, 6 and 12 of the UNCRC

[80] UNCRC General comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6), Paragraphs 6, 24, 25 & 48

[81] UNCRC General comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6), Paragraphs 12, 27, 38, 39, 48 & 69

Section 5 Recommendations

The OCO is of the view that the following measures need to be taken to address the challenges arising with respect to AONs.

5.1 Legislation

5.1.1 The Disability Act 2005

The UNCRC Committee has stated that it 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. For this reason, implementation measures should be directed at the child’s needs as a whole.

It is therefore critical that the assessment and identification of a child’s development needs is holistic in nature and multidisciplinary in approach. This should be explicitly provided for in the legislation.

As enacted, the 2005 Act mechanism is an assessment of the need for services, rather than an assessment of the health and development needs of the child or young person. The only gateway to access these services is through a disability finding. For this reason, if an Assessment Officer finds that a child does not have a disability, a Liaison Officer cannot provide a Service Statement, regardless of the child’s other identified needs. The 2005 Act is a diagnosis led, rather than a needs led, model.

The CRPD Committee has expressed its concern that the laws and policies of States still approach disability through a diagnosis led model, despite the incompatibility of that model with the CRPD. According to the CRPD Committee, the persistent use of such paradigms fails to acknowledge persons with disabilities as full rights holders. They are instead ‘reduced’ to their impairments. In contrast, the rights-based model of disability recognises that disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of rights. It acknowledges that disability is one of several layers of identity, and that human rights are interdependent, interrelated and indivisible.[82] At the conclusion of Ireland’s last reporting cycle, the UNCRC Committee specifically recommended that the State adopt a human rights-based approach to disability.

Furthermore, the 2005 Act contains an adult definition of disability. With its emphasis on productivity and participation, this definition fails to account for the child and their needs. For this reason, the HSE has taken the position that a child who requires services for more than 12 months has a disability, even though this approach runs counter to the PDSCYP model of focussing on early screening and categorisation based on complex or non-complex need. Focus should be on the early identification of needs rather than the early diagnosis of disability.[83]

Having regard to Article 42A.1 of the Constitution, Ireland’s obligations under European and international human rights standards, and the OCO’s positive duty to monitor and

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[82] CRPD General comment No. 6 (2018) on equality and non-discrimination, Para. 2, 8 & 9

[83] UNCRC Concluding observations on the combined third and fourth periodic reports of Ireland adopted by the UN-CRC Committee at its seventy-first session (11 -29 January 2016)

review generally the operation of legislation concerning matters that relate to the rights and welfare of children,[84] we are of the view that the 2005 Act should be reviewed and particular consideration be given to:

a section setting out the following guiding principles which must inform the interpretation and implementation of the provisions in the 2005 Act that concern children:

- Children are recognised as independent rights-holders;
- Children have a right to have their best interests treated as a paramount consideration in all actions and decisions affecting them;
- Children have a right to survival and development to the maximum extent possible;
- Children with disabilities are entitled to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community;
- Children have the right to non-discrimination and the State must take active steps to identify children, who may require special measures for the recognition and realisation of their rights;
- Children have a right to the enjoyment of the highest attainable standard of health;
- Children with disabilities should be provided with reasonable accommodation, and effective individualised support measures in educational environments that maximise academic and social development, consistent with the goal of full inclusion;
- Children have a right to express their views freely and to have due weight given to their views, in accordance with their age and maturity; and
- Children are entitled to timely decision-making and accountability by decision makers.[85]

the amendment of the definition of disability at section 2 of the 2005 Act to a definition which is rights-based, child-centred and inclusive;

the amendment of section 7 of the 2005 Act to ensure a best interest, holistic, multidisciplinary, needs-based approach to AON;

the amendment of section 8(9) of the 2005 Act to remove reference to a special educational needs assessment referral under the EPSEN Act, as necessary (see 5.1.2 below); and

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[84] Section 7(1)(g) of the 2002 Act

[85] In the DCYA 'Review of the Child Care Act 1991 July 2020 Consultation Paper', the Department proposed the introduction of a similar new section on guiding principles which would provide guidance on the implementation of that Act in its entirety. This follows the approach adopted by the drafters of international human rights instruments, including the UNCRC and the CRPD, in setting out general principles at the outset.

the amendment of section 18 of the 2005 Act to expand the powers of the Disability Appeals Officer to provide compensation as a remedy for breaches under the Act (see 5.4.2 below).

5.1.2 The EPSEN Act

The EPSEN Act, in contrast to the 2005 Act, is more akin to a needs-led rather than a diagnosis-led model. Under the EPSEN Act, a special educational needs assessment should result in a statement of the nature and extent of the child's disability (including in respect of matters that affect the child overall as an individual), and a Statement of Services which the child will need so as to be able to participate in and benefit from education and to develop his or her potential generally.[86]

The right to accommodation in education is enshrined in Article 42.4 of the Irish Constitution, and is not subject to progressive realisation. The Irish Constitution, therefore, places the State under a high level of obligation to meet the educational needs of all children[87]. The OCO is firmly of the view that legislative underpinning for the special educational needs of children is vital to ensuring that children's needs are identified and met in a timely and appropriate manner. Therefore, the commencement of sections 3 to 13 of the EPSEN Act must be considered in concert with a review of the 2005 Act, as outlined at [5.1.1].[88]

5.2 Coordination

5.2.1 Whole of Government Approach

In addition to the recommended review of the 2005 Act, having regard to the EPSEN Act and, specifically, commencement of sections 3-13 of the EPSEN Act, the State must undertake a review of the access criteria for all services for which a diagnosis is still generally required, and ensure a clear pathway to services for all children according to need.[89]

This would include a needs-based framework for access to services provided by voluntary bodies, and education services, such as special classes, the school transport scheme, home tuition, special needs assistants, and the assisted technology scheme. A confirmed diagnosis should no longer be a requirement for a child's admission to a specialist pre-school or school. In addition, AON applications on behalf of children should be dealt with as a single procedure under the 2005 mechanism, and the practice of separate early years and school aged lists for AON should be eradicated.

Similarly, a consistent, rights-based, child-centred and inclusive definition of disability needs to be adopted by all Government departments and agencies responsible for meeting the needs of children.

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[86] Section 4(6) of the EPSEN Act

[87] Dr Conor O'Mahony, Educational Rights in Irish Law (Thomson Round Hall, 2006), Chapter 6, paras 6-37 to 6-63

[88] According to NEPS, this review needs to be in the context of the changed policy position in education in moving towards a needs-based approach with an emphasis on early intervention, prevention, inclusion and participation.

[89] NEPS informed the OCO that this will require the development of a needs based framework to support the identification of complex need.

5.3 National Strategy and Resourcing

5.3.1 Independent Expert Group

The OCO recommends that an Independent Expert Group be established to review the 2005 Act, having regard to the EPSEN Act, and related legislation which impacts the provision and delivery of AONs and special educational needs assessments. The Independent Expert Group will identify the amendments required to bring the 2005 Act in line with a rights-based and needs-based approach to disability.

This Expert Group should report its findings to the Minister for Health, the Minister for Education and Skills, the Minister for Children, Disability, Equality and Integration, the Minister of State for Disability, the Minister of State for Special Education and Inclusion, and the Oireachtas.

5.3.2 Role of the Oireachtas

The OCO is supportive of the Government's commitment to 'work with other parties in the Oireachtas to establish a Joint Oireachtas Committee to assist in monitoring and implementing the provisions in the Convention on the Rights of People with Disabilities (UNCRPD)'.[90]

The OCO considers there to be scope for a Special Joint Oireachtas Committee on the Rights of Persons with Disabilities to have broad responsibility for scrutinising legislative amendments and Government activities in the area of disability, most notably, a consistent human rights-based approach to disability and the CRPD. The creation of this Joint Oireachtas Committee would demonstrate the State's commitment to protect and affirm the rights of people with disabilities pursuant to Ireland's ratification of the CRPD.

5.3.3 Inter-Departmental Group

The OCO also proposes the formal establishment of an Inter-Departmental Group (IDG) on children with disabilities, which should report to the Minister for Health, the Minister for Education and Skills, the Minister for Children, Disability, Equality and Integration, the Minister of State for Disability, and the Minister of State for Special Education and Inclusion. Membership of this IDG should include representatives from the Department of Health, the Department of Education and Skills, the Department of Children, Disability, Equality and Integration, the HSE, the NCSE, and HIQA.[91]

The establishment of this IDG would be in furtherance of the Government's commitment to 'Build on the cross-cutting arrangements in place between the Department of Health, the Department of Education and Skills, and the Department of Children and Youth Affairs to enhance collaboration across the three sectors on children's disability issues. (DH, DES, NCSE, DCYA and HSE)'.[92]

Further to the UNCRC Committee's recommendation that the State adopt a human rights-based approach to disability and establish a comprehensive strategy for the

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[90] Page 78, Programme for Government, June 2020

[91] There is precedent for establishing such a group, with recent legislation on child welfare and protection requiring Government to establish the Children First Interdepartmental Implementation Group (CFIDIG). Membership of the CFIDIG includes all government departments, Tusla, the HSE and An Garda Síochána.

[92] Better Outcomes Brighter Futures: The National Policy Framework For Children and Young People, 2014 -2020 at para. 2.18

inclusion of children with disabilities,[93] the OCO recommends that this IDG create a comprehensive strategy and a budgetary proposal for the full implementation of PDSCYP, including the full 'establishment of the Progressing Disability Services for Children and Young People (0- 18 years) Network Teams' as envisaged in the Programme for Government.[94] The IDG should prioritise actions which address the early identification, early intervention, and early treatment of children with disabilities. In the Programme for Government, the Government commits to 'prioritise early diagnosis interventions and access to services'.[95] This strategy should set out indicators for the measurement of outcomes for the effective functioning of the AON process across CHOs.

It is important that all members of the IDG commit to working towards the agreed outcomes, taking on responsibility for progressing these within their respective departments and influencing wider policy development. As such, the IDG should set out clear, measurable objectives in order to achieve identified outcomes, and assess objectives regularly to ensure that they continue to be aligned with agreed outcomes.

5.3.4 Additional Resources

Even where the available resources are demonstrably inadequate, the State is still obliged to strive to ensure the widest possible enjoyment of children's right to health and development under the prevailing circumstances. For this reason, the OCO is of the view that further significant investment by the Department of Health and the HSE is also needed in this area.

The HSE National Service Plans for 2019 and 2020 gave a projected outturn of 9% of AONs completed within the timeframes provided for in the 2007 Regulations. This would suggest a tenfold increase in expenditure requirement (not accounting for potential economies).[96]

The Programme for Government commits to 'seek to reduce the waiting times for assessment of need under the Disability Act 2005, through the full-year provision of additional therapy posts'.[97] In order to address the issue of protracted waiting lists, the Department of Health and the HSE must ensure the provision of adequate financial, technical, and human resources to Disability Teams for the administration and recruitment of additional therapists, to manage AONs in a timely manner.

The OCO welcomes the recent announcement from the Minister for Health and the Minister of State for Disability to invest a further €7.8m in tackling the AON waiting list. However, the low numbers of AONs being completed at present suggests a much greater resource commitment is required in the longer term.[98]

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[93] UNCRC Concluding observations on the combined third and fourth periodic reports of Ireland adopted by the UNCRC Committee at its seventy-first session (11 -29 January 2016)

[94] Page 78, Programme for Government, June 2020. The HSE informed the OCO that notwithstanding the pressures of COVID-19, the HSE intention is to have all Children's Disability Networks in place at the end of 2020.

[95] Page 78, Programme for Government, June 2020

[96] In the National Service Plan 2020, the closing recurring disability services budget for 2019 was €1.9b. The HSE increased its disability budget spend by €30.5m in 2020, with an extra €6m allocated for disability needs assessments.

[97] Page 78, Programme for Government, June 2020

[98] According to the Irish Independent, there were 5,083 overdue assessments at the end of March, less than 3% of which were because of exceptional circumstances ('€7.8m to go towards clearing backlog of children on waiting lists for assessment', Irish Independent, 10/09/20)

5.4 Accountability

5.4.1 Standards

The OCO recognises and supports the development by HIQA of a new set of National Standards for the Assessment of Need for Children with Disabilities in order to create an overarching framework of high level principles through which actual care can be consistently measured against optimal care.

These new HIQA Standards should be aligned with wider National Children's Standards in order to improve the experience of all children using health and social care services by promoting clarity, consistency and equity within and between services.

5.4.2 Complaints Mechanism

The OCO further recommends that the State ensure that a functional and accessible complaints mechanism remains in place for children to seek and obtain effective and timely remedies.[99]

Where the statutory timelines as set out in the 2005 Act have been breached, the Disability Appeals Officer should seek to exercise their powers under the 2005 Act by applying to the Circuit Court for an enforcement order three months after the non-implementation of their recommendation. Unfortunately, to date, the Disability Appeals Officer has never applied to the Circuit Court for an enforcement order.

Alternatively, where exigent circumstances exist, appropriate reparation in the form of the reimbursement of private medical fees incurred by a parent in securing alternative services as a result of a delay in receiving an AON for their child, should be considered.[100] This may necessitate the legislative expansion of the powers of the Disability Appeals Officer to provide such compensation as a remedy for breaches under the Act.[101]

5.5 Data Collection

The State must take active steps to identify individual children and groups of children, who may require special measures for the recognition and realisation of their rights.

The OCO recommends that the HSE collect and create a central database of AON data, which is accessible to all therapists, clinicians and administrators involved in the AON process. The database should allow access to information on a real-time basis in relation to the waiting times for appointments and the availability of services detailed in the

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[99] In the High Court test case of C.M. (A Minor) -v- The Health Service Executive [2020] IEHC 406 Barr J determined that the 2005 Act complaints process constituted 'a reasonable and efficient means of dealing with the majority of complaints that are likely to arise in connection with an assessment of needs, or a service statement' (para. 57) noting that 'It is stated that the HSE has devoted significant resources to ensure that the statutory complaints process runs smoothly. The complaints office dealing with complaints regarding assessments of needs has been fully staffed since October 2018. She has stated that a backlog which once existed in dealing with such complaints, has now been completely cleared. Between January and April of 2019, the complaints office received 291 complaints, of which 246 were completed (meaning that recommendations were made, or complaints were rejected) within 30 working days and on average these files took 22 days to resolve. She states that that was achieved notwithstanding a 17% increase in complaints made year on year for the same period in 2018. She went on to state that in straightforward cases, recommendations have been made within as short a time as seven days' (para. 55)

[100] The HSE informed the OCO that it is concerned that limited State resources would be used for compensation rather than directing resources to providing appropriate services.

[101] i.e. a revision of section 18(5) of the 2005 Act

Service Statement. This would allow Disability Teams to plan and respond appropriately.

The HSE should evaluate the data collected in order to identify problems, assess progress in strategy implementation, and inform national policy development. The HSE should also use this data to monitor the implementation of the new SOP to ensure that it does not lead to further delays or a diminishment in standards.

Statistics in relation to the commencement and completion of assessments, and the finalisation of Service Statements, should be published in the quarterly reports along with targeted solutions for any shortcomings.

5.6 Awareness Raising, Communication and Engagement

The OCO recommends that the HSE create informational materials for both parents and children to guide them through the AON process. These informational materials should be made available upon acknowledgement of receipt of a child's application, and should be child-friendly when directed at children and young people.

The OCO also recommends that the HSE commit to meaningful engagement with children with disabilities, their parents, professional bodies and service users, in order to ensure that SOPs are aligned with a rights-based and needs-based approach and are based on the new HIQA Standards and the best available evidence. In furtherance of this objective, the HSE should adopt a child rights based approach when engaging with, and hearing, children with respect to the AON process and other matters affecting them.

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