

**Oireachtas Joint Committee on Children, Disability, Equality and Integration**  
**Opening Statement by the Ombudsman for Children, Dr Niall Muldoon**  
**Tuesday, 1st December 2020**

I would like to thank the Joint Committee on Children, Disability, Equality and Integration for inviting me to appear today to discuss **'Unmet Needs'**, our report on the challenges faced by children in Ireland who require an assessment of their needs.

As members of the Committee are aware, the Ombudsman for Children's Office (OCO) is an independent statutory body, which was established under the Ombudsman for Children Act 2002 (as amended). The OCO has two core statutory functions, namely:

- to promote the rights and welfare of children under 18 years of age.
- to examine and investigate complaints made by, or on behalf of, children about the administrative actions of public bodies, schools or voluntary hospitals that have, or may have had, an adverse effect on a child.

The rights and welfare of children with disabilities has been a strategic priority for my Office since 2016. In our Strategic Plan for the period 2019 to 2021, we committed to continue to pursue the progressive realisation of the rights of children with disabilities.

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

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. This report raises serious concerns about ongoing violations of the rights of children with disabilities. This includes the significant delay in accessing an assessment of need (AON), despite the HSE's legal obligation to commence an AON within three months of receipt of a child's application.

Between 2017 and 2019, the OCO received 95 complaints from parents regarding their child's access to a statutory AON. Parents related their concerns about the potential adverse effect of this delay on their child's development.

Children's earliest years are the foundation for their physical and mental health, emotional security, cultural and personal identity, and developing competencies. While the report highlights the stories of Andrew, Lucy, Michael and Sarah, we know that some 6,058 children are currently overdue an assessment, with less than 10% of assessments being carried out within the statutory timeframe.

As members of the Committee know, in September 2004, the Government launched the National Disability Strategy (NDS) with the aim of supporting the equal participation of people with disabilities in society. It was envisioned that the NDS would lead to an equitable reconfiguration of disability services.

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 services required by a person with a disability. The EPSEN Act provided for an assessment of special educational needs so that a child with such needs may be educated in an inclusive environment. While the 2005 Act has commenced in full, sections 3 to 13 of the EPSEN Act, which concern the assessment of special educational needs, have, to this day, not been commenced.

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.

A deficiency of resources allocated to meet the demand for AONs has also hampered the effectiveness of the 2005 Act mechanism. 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. The HSE's own National Service Plan for 2020 projected that only 9% of AONs would be completed on time. In addition, there is a reported lack of consistency in approach to AONs across the Community Healthcare Organisations (CHOs).

Furthermore, as members of the Committee know, since the 2005 Act came into force, national policy and programmes have moved towards a needs-led, rather than diagnosis-led, service model. For this reason, the 2005 Act mechanism, as drafted, is at odds with the principles that now underscore national policy in this area.

Having considered the perspectives shared by children and parents, we propose the following priorities for action to address the challenges arising with respect to AONs:

1. We call on this Committee to advance a review of the 2005 Act, with particular consideration be given to:
  - a section setting out guiding principles which must inform the interpretation and implementation of the 2005 Act, including the recognition that 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;
  - the amendment of section 2 to a definition of disability which is rights-based, child-centred and inclusive;
  - the amendment of section 7 to ensure a best interest, holistic, multidisciplinary, needs-based approach to AON; and
  - the amendment of section 18 to expand the powers of the Disability Appeals Officer to provide compensation as a remedy for breaches under the Act, in an effort to drive the State toward a better adherence to its statutory obligations and timelines.
2. The commencement of sections 3 to 13 of the EPSEN Act must also be considered. 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.
3. There must be a whole of Government review of the access criteria for all services for which a diagnosis is still generally required, to ensure a clear pathway to services for all children according to need.
4. 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.
5. The OCO is supportive of the establishment of the Joint Oireachtas Committee on Disability Matters to assist in monitoring and implementing the provisions in the Convention on the Rights of People with Disabilities (UNCRPD). The State's commitment to protect and affirm the rights of people with disabilities, would be further cemented by the ratification of the Optional Protocol to the UNCRPD, which would allow persons with disabilities to make individual complaints to the UNCRPD Committee.

6. The OCO proposes the formal establishment of an Inter-Departmental Group (IDG) on children with disabilities, which should prioritise actions which address the early identification, early intervention, and early treatment of children with disabilities.
7. The OCO considers that significant investment is needed in this area. The current projected outturn of 9% of AONs completed within the timeframes would suggest a tenfold increase in expenditure requirement. The State, via the HSE, must ensure the provision of adequate financial, technical, and human resources to the National Disability Children and Families Teams to manage AONs in a timely manner.
8. The OCO supports the development by HIQA of a new set of National Standards for the Assessment of Need for Children with Disabilities. The OCO proposes that these be aligned with wider National Children's Standards in order to improve the experience of all children using health and social care services.
9. The OCO recommends that the State ensure that a functional and accessible complaints mechanism remains in place, and that 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, be considered.
10. The OCO recommends that the HSE collect and create a central database of AON data in order to identify problems, assess progress in strategy implementation, and inform national policy development.
11. The also OCO recommends that the HSE create informational materials on the AON process for both parents and children and commit to meaningful engagement with children regarding the AON process.

It is clear from our report 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 Ireland.

As members of the Committee may be aware, the UNCRC Committee has urged the State to incorporate the UNCRC into domestic law 'as a matter of priority'. It remains an unfinished project, and one which I recommend that we complete. Incorporation would give children, young people and their representatives the power to go to court to enforce their rights, with the effect of building children's rights into the fabric of decision making in Ireland.

My renewed thanks to the Committee for inviting my Office to attend today. I am happy to take questions if I can be of further assistance.