



Tithe an
Oireachtais
Houses of the
Oireachtas

**An Comhchoiste um Leanaí, Comhionannas,
Míchumas, Lánpháirtíocht Agus Óige**
Tuarascáil maidir le Measúnachtaí ar Riachtanais Leanaí

Feabhra 2023

Joint Committee on Children, Equality, Disability, Integration and Youth
Report on Assessments of Need for Children

February 2023



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AND YOUTH**

Report on Assessments of Need for Children

February 2023

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FOREWORD

The Joint Committee on Children, Equality, Disability, Integration and Youth (the Committee) undertook, as part of its Work Programme for 2020-21 and 2021-22, to examine a report by the Ombudsman for Children's Office entitled 'Unmet Needs'. That report details the challenges faced by children in Ireland who require an assessment of their needs and supports and interventions that flow from that assessment and suggests a number of measures that could be introduced to better meet these needs. The interventions required are things like speech and language therapy, physiotherapy and psychology services, for example.

As part of its examination of the issues detailed in that report, the Committee invited a number of stakeholders and experts in the field to appear before it over the course of six Committee meetings. The Committee also invited written submissions from a selection of stakeholders. Links to the transcripts and the submissions are contained in Appendix 2. A joint meeting of this Committee and the Disability Matters Committee was also held on 2 June 2022 to discuss a range of issues associated with Progressing Disability Services.

Many of the issues flagged and recommendations made, such as the need for more collaboration with therapists and parents, echo those that have been made from many quarters over many years, by various stakeholders. It became clear during the Committee's deliberations that the same problems have existed for over a decade. They have been consistently highlighted by those working in the sector and by parents. Successful solutions have either not been found or else not been implemented. The damage done to children and their families is enormous. The stress the broken system causes to those working in the sector is likely immense, as is the drain on resources that patching it up costs.

All of this begs the question of why? Why have children with disabilities or additional needs been failed so badly, for so long? What is the solution? Is it a lack of political will? Or a lack of resources? What can be done? Who is responsible for doing it?

In an attempt to answer some of these questions, this report begins with a look back at what has been done when and details some developments and failures over the

last few years. Then it examines the problem under five key issues and makes corresponding recommendations. Some information about how assessments and interventions are provided in other jurisdictions is also included, in the hope that it might inspire some ideas or collaboration.

The Committee hopes that this report helps in the development of solutions and that by taking this look back it contributes to transparency and accountability within children's disability services.

The assessment of need process is far from resolved. It is arguably at another critical juncture as we await the development of a new Standard Operating Procedure and an audit of Progressing Disability Services. The Committee wish to assure both children and adults with disabilities, parents, carers and those working in the sector that the publication of this report does not mark an end to its consideration of these issues. The Committee will be watching closely to see what next steps are taken and will continue to do what it can to highlight the issues and make constructive recommendations.

The Committee is extremely grateful for the input from all stakeholders, from correspondence to testimony given during public sessions, especially from parents. I said in closing at one of our first meetings on this topic that people should not have to tell their stories to their local Deputy or anybody, that the system should not be like that, but we appreciate being able to hear first-hand from people exactly what they are going through, so that, hopefully, we can use it to help fight the battle alongside them.



Kathleen Funchion T.D.

Cathaoirleach

14 February 2023

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RECOMMENDATIONS

The Committee recommends that:

1. The disability capacity review action plan should be rights based and UNCRPD compliant and should be published immediately.
2. The Budget 2023 allocation should be increased significantly to ensure the provision of adequate financial, technical, and human resources for disability services to meet the investment targets set out in the Disability Capacity Review and to improve the timeliness of AONs.
3. The legacy impacts of austerity cuts must be curtailed and remedied as a matter of urgency.
4. There needs to be an acknowledgment of the levels of resourcing required at all levels politically and within the HSE, in order to address the crisis in the disability sector.
5. The terms and conditions for Section 39 workers are made equal to those of their public service counterparts.
6. Wages for therapists should be increased, hours should be decreased (while retaining optional overtime) and tax breaks/incentives should be created for those working in the sector.
7. Student therapists must receive remuneration for their internship and placement work.
8. Special grants towards fees and costs associated with training for therapists should be established (in addition to the universal SUSI grant application process).
9. Working conditions within the disability sector must be improved.
10. The Department and HSE should ensure that exit interviews are conducted with all HSE staff who leave the service and improve working conditions based on insights from these.

11. The recruitment process for hiring staff involved in providing interventions and assessments must be reformed to ensure a quicker, more efficient system.
12. The panel-based system of recruitment should be replaced with a new system, which should be developed by working in conjunction with health and social care professionals. This should not impact on or pause hiring in the meantime.
13. 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.
14. The options to support the recruitment of staff for the Children's Disability Network Teams currently being explored by the HSE need to be actioned, resourced and implemented now.
15. There must be an immediate increase in health and social care places at third level and engagement at all years of the course with the HSE and CDNTs to foster an atmosphere of ownership of progression to employment in these networks.
16. Shorter college courses for therapists should be developed, and insights should be drawn from other countries, where, in areas such as speech and language therapy and occupational therapy only take two years.
17. Initiatives related to hiring internationally must be implemented and capitalised on, including the relocation allowance.
18. Consideration should be given to building in a mandatory term of service in Ireland for those that train here.
19. A clear plan must be communicated to parents regarding the situation with AONs going forward, including timelines and information on what measures are being taken, budgetary and otherwise, to get children the services they need.
20. The audit of Progressing Disability Services must begin now and report back in quarter one of 2023. Independent experts must be involved. It should report to the Minister of State for Disability, the Minister for Health, an Taoiseach and the Committee on Children, Equality, Disability, Integration and Youth simultaneously.

21. Responsibility for delivery of essential services for disabled Children should lie jointly with the Department of Health, Department of Children, Equality, Disability, Integration and Youth *and* the Department of the Taoiseach until such a time when the backlogs are cleared and confidence is restored.

22. The Roadmap, that was to be made available in June, must be progressed and should be published by end February 2023.

23. A central ICT database should be created that collects AON data in order to identify problems, assess progress in strategy implementation, and inform national policy development. The Committee on Children, Equality, Disability, Integration and Youth should be pro-actively updated with data on how AON and PDS figures are progressing, on a monthly basis, in the way that others Oireachtas Committees are updated on key metrics under their remit. The new ICT system must be successfully implemented within the HSE as a matter of urgency.

24. The work of the Interdepartmental Group on Children with Disabilities, which includes members from the Departments of Health, Education and Children, Disability, Equality, Integration and Youth, as well as associated agencies, must be intensified and that group should be facilitated to have more of an impact in terms of resolving the issues identified in this report.

25. An education campaign should be launched to provide parents, care-givers and children with accessible information about the AON process.

26. Appropriate tools, guidance and supports should be provided for assessment officers and all those working in disability services generally.

27. Input from disabled people, families, carers and therapists should be central to the design of the interim guidance and of any new SOP, in addition to the work of the National Clinical Programme for People with Disabilities generally.

28. Where schools are involved in the AON process, they must be properly resourced, either through in-house multidisciplinary teams, regional special education centres or mobile special education support and assessment teams.

29. Communication with schools about their role in the AON process, once clarified, needs to be improved and buy-in and collaboration with them established.

30. The Progressing Disability Services audit should assess how the National Clinical Programme for People with Disabilities is working, including analysing how many people with lived experience of having a disability are involved, whether that amount is enough, and whether they are being enabled to provide meaningful input into the relevant fora and policies.

31. Assessments should be followed up with appropriate signposting of services to support those who need them throughout their life.

32. The Department should reimburse parents and caregivers, on a case-by-case basis, in respect of private medical fees incurred in securing alternative services, in circumstances where there are delays in receiving an assessment for their child through the public system.

33. A review of the Disability Act should be undertaken, but under the following specific conditions:

A. The Disability Act and ESPEN Act must be reviewed in tandem. The fact that different Government departments have responsibility for these pieces of legislation should not be a barrier to the 2005 Act being considered in the context of the review of the 2004 Act, and, if necessary, changes being made to both at that stage.

B. Any review of the Disability Act should not remove or dilute any rights contained therein, including the right to a comprehensive, complete assessment of need.

C. The legislation must be child centred, rights-based, be UNCRPD compliant and be underpinned by a needs-led rather than a diagnosis-led model.

D. The review should be undertaken by an independent expert group, to include representatives of Disabled Persons Organisations (DPOs) and their advocates.

E. As with all initiatives aimed at improving disability services, the review of the Act and implementation of changes arising from it must take a coordinated, whole of Government approach.

F. The review of the Act should not impact service provision in the meantime. Shortcomings within the Act are not an acceptable justification for the failure to provided assessments and interventions to all children who need them in a timely manner.

G. Any review of the Disability Act must preserve the element that refers to provision “without regard to cost or capacity” and should impose a right to interventions as well as assessments within statutory timeframes and without regard to cost.

34. The review of the Disability Act 2005 should consider:

A. 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.

B. The amendment of section 2 to a definition of disability which is rights-based, child-centred and inclusive.

C. The amendment of section 7 to ensure a best interest, holistic, multidisciplinary, needs-based approach to AON.

D. 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.

35. The UNCRPD Optional Protocol should be ratified without any further delay.

36. The UNCRC should be incorporated into domestic law as a matter of priority.

37. HIQA must be resourced to provide appropriate and up-to-date standards for AON. These should be developed as a priority.

38. The HSE must work with therapists collaboratively to ensure that policies and procedures are CORU compliant.

39. There should be an immediate cessation of the SOP.

INTRODUCTION AND WITNESSES

The aim of this report is to look at developments in children's disability services over the last several years to underline the need for serious reform now and to make recommendations as to how this might be best achieved. The report draws on testimony from families, therapists, the HSE, information provided by the Department of Health and other experts over six meetings of the Committee from 2020 to 2022.

The sections included are:

- Background: what has happened so far
- Key Issue 1: Resources and Capacity
- Key Issue 2: Recruitment and retention
- Key Issue 3: Systems and Organisation
- Key Issue 4: The Assessment
- Key Issue 5: Standards, Acts and Conventions
- International Insights: a survey of 30 other jurisdictions

There are two Acts relevant to the assessment of needs process for children with additional needs or a potential disability in Ireland:

1. [The Disability Act, 2005](#)

The 2005 Act provides for an assessment of need to determine the health or educational services required by a person with a disability. It defined the assessment mechanism and its scope. Section 9 of this Act stipulates that an assessment must be completed within six months.

2. [Education for Persons with Special Education Needs Act, 2004](#)

The 2004 Act, often referred to as 'EPSEN', provides for an assessment of special educational needs so that supports could be provided for a child with such needs that enable them to be educated with children who do not have such needs wherever possible.

The EPSN Act has not yet been fully commenced, although it was intended to operate in conjunction with the Disability Act 2005. Therefore, students who require

an assessment of their special educational needs often apply for an assessment of needs under the Disability Act 2005. This adds to waiting lists and resource problems.

Glossary

Abbreviations and terms used throughout this report include:

AON = Assessment of Need

CDNTs = Children's Disability Network Teams. These are the regionally based teams that provide assessments and interventions to children

Minister Rabbitte = Anne Rabbitte TD, Minister of State with responsibility for Disability, assigned to the Department of Health and the Department of Children, Equality, Disability, Integration and Youth

SOP = Standard Operating Procedure

The Committee = The Joint Committee on Children, Equality, Disability, Integration and Youth

The Ombudsman = Dr Niall Muldoon, Ombudsman for Children

UNCRPD = The United Nations Convention on the Rights of Persons with Disabilities - an important international human rights treaty that informs many of recommendations in this report

The AON process is generally as follows:

1. If a child has a suspected disability the parent can apply to their local HSE Assessment Officer for an Assessment of Need (AON). They fill in an AON application form.
2. The Assessment Officer may seek more information about the child that will help to show the nature and level of difficulty experienced by the child.
3. If the child needs an assessment, the Assessment Officer should arrange this referral to the local Assessment Officer within 3 months of receiving the completed application form. Once this referral is made there is a further 3

months to assess the child and complete the Assessment Report. These timelines are provided for in the 2005 Act, and on [the HSE's online guide for parent/guardians](#), but in reality there are usually delays.

4. The child is assessed by one or more clinicians, either in-person, or online in some cases due to Covid-19 restrictions.
5. The child receives an Assessment Report and if they have been found to have a disability or additional needs a Service Statement listing what health services and supports will be provided for them. Sometimes this Statement refers the child for a second more comprehensive assessment if more information about them is needed.
6. Based on the Service Statement, services and supports aimed at addressing emotional, learning, physical or other needs are provided to the child by local teams including Speech and Language therapists, Occupational therapists, Psychologists, Physiotherapists and so on.

There are two waiting lists for children seeking an initial AON, one for 0-5-year-olds and one for children aged 6 or over. Children can spend years on these lists and 'age out' or reach the maximum age on the first list before receiving an assessment or intervention, and then must join the waiting list for older children and begin the wait for assessments and services again.

Parents often successfully take the Health Service to court to get enforcement orders to force access to AONs and therapeutic services for their children.

On 1 December 2020 there were 6058 children overdue an AON¹. On 30 September 2022 there were 4685². These figures are separate to the roughly 10,000 who received an assessment that was found to be in reach of the Disability Act, many which will have to be re-done. The detrimental effect that not getting the required therapies, on time, can have on children has been well documented, as has the benefit of early intervention. Accessing timely assessments and interventions can be life changing. As

¹ See Ombudsman's contribution during meeting of 1 December 2020 for more on this. Available at: [main.pdf \(oireachtas.ie\)](#)

²This figure was provided by the Department of Health and HSE via Minister Rabbitte's office

the Committee heard, particularly during its meeting of 8 December 2020, it can be the difference between a child being enabled to live at home or being placed in residential care, or parents being unable to cope or forced to hand over their child to TUSLA³. It can mean reaching milestones that improve quality of life or missing them. It can mean avoiding invasive procedures and it can have huge impacts on mobility, speech, independence and opportunities to participate in education.

The HSE introduced a new Standard Operating Procedure (SOP) for carrying out AONs in January 2020, in an effort to standardise and improve the AON process. As discussed in more detail in the background section, this too has moved many children from one waiting list to another and was found to be in breach of the Disability Act, 2005.

These issues have been well-known for some time. As such, this report first explores developments over the last number of years, to illustrate the protracted nature of the problem, to explore why reform has failed and to emphasise why drastic action is now required.

Some primary research in the form of an international survey, was also carried out, to gather contemporary data on how the assessment of needs process and related issues are dealt with in other jurisdictions. This was carried out using the European Centre for Parliamentary Research and Documentation network (ECPRD), which is a tool for inter-parliamentary cooperation. This is explored further in Appendix 1. It is hoped that this data will provide the relevant Departments, policy-makers and agencies, including the HSE, with some food for thought in terms of solutions or innovations, or even inspire some international collaboration. Every step possible must be taken urgently to stop failing children and start meeting their needs.

³ Meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

WITNESSES

The Witnesses who came before the Committee were as follows:

1 December 2020

Ombudsman for Children's Office

- Dr Niall Muldoon, Ombudsman
- Dr Karen McAuley, Head of Policy Department
- Ciara McKenna-Keane, External Investigator

8 December 2020

Enough is Enough

- Vanessa Murphy
- Linda Comerford

Psychological Society of Ireland

- Mark Smyth

Association of Occupational Therapists of Ireland

- Odhrán Allen

Other

- Gareth Noble, Child Rights Solicitor
- Naomi Mulvany, Legal Assistant

15 December 2020

- Anne Rabbitte TD, Minister of State with responsibility for Disability, assigned to the Department of Health and the Department of Children, Equality, Disability, Integration and Youth
- Jenny Andersson, Official
- Noel Byrne, Official

2 March 2021

HSE

- Dr Cathal Morgan, Head of Operations with Disability Services

- Angela O'Neill, National Disability Specialist with lead responsibility for Assessment of Need
- Breda Crehan Roche, Chief Officer for Community Healthcare Organisation Area 2
- Professor Malcom MacLachlan, Clinical Lead of the National Clinical Programme for People With Disability

11 May 2021

- Anne Rabbitte TD, Minister of State with responsibility for Disability, assigned to the Department of Health and the Department of Children, Equality, Disability, Integration and Youth
- Jenny Andersson, Official
- Noel Byrne, Official

22 March 2022

Ombudsman for Children's Office

- Dr Niall Muldoon, Ombudsman
- Dr Karen McAuley, Head of Policy Department
- Ciara McKenna-Keane, External Investigator

HSE

- Paul Reid, CEO
- Professor Malcolm MacLachlan, Clinical Lead for People with Disabilities
- Bernard O'Regan, Head of Operations - Disability Services
- Angela O'Neill, National Disability Specialist - Community Operations
- Anne O'Connor, Chief Operations Officer
- T.J. Dunford, Head of Primary Care Operations

2 June 2022

- Anne Rabbitte TD, Minister of State with responsibility for Disability, assigned to the Department of Health and the Department of Children, Equality, Disability, Integration and Youth
- Siobhán McArdle, Official
- Deirdre Comiskey, Official
- Audrey Hagerty, Official
- Jason Doran, Official
- Thomas Morrin, Official

HSE

- Paul Reid, CEO

- Yvonne O'Neill, National Director of Community Operations
- Professor Malcolm MacLachlan, Clinical Lead for People with Disabilities
- Bernard O'Regan, Head of Operations - Disability Services
- Angela O'Neill, National Disability Specialist - Community Operations
- Breda Crehan Roche, Chief Officer for Community Healthcare Organisation Area 2

BACKGROUND

In 2007 there were 1138 applications for AONs⁴.

In 2011 the National Disability Authority published a report on the practice of Assessment of Needs under the Disability Act. It highlighted inconsistent and lacking service provision, increasing referrals from the education sector and significant differences in the systems, amount of time and resources being used to assess children with disabilities across teams⁵. An over-reliance on diagnosis as opposed to needs was also highlighted.

In 2016 an internal HSE review of same confirmed the approach to assessment of need was not consistent across the country.

In 2018 there was 5060 applications for AONs. Just 8.8% were completed on time. i.e., within the statutory timeframes prescribed by the Disability Act, 2005 of six months⁶.

The HSE National Service Plans for 2019 and 2020 projected that just 9% of AONs would be completed within the statutory timeframes⁷.

In 2020, up to December 10th, there were 992 complaints received by the HSE regarding children not getting timely AONs. Of those, 691 investigations were completed, with 634 complaints being upheld. That is 91.75%.

⁴ Figures provided by the HSE for the Ombudsman's report. Available at [15438 OCO Assessment of Need Report Interactive.pdf](#)

⁵ [National Disability Authority Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005 - National Disability Authority \(nda.ie\)](#)

⁶ Figures provided by the HSE for the Ombudsman's report. Available at [15438 OCO Assessment of Need Report Interactive.pdf](#)

⁷ Available at [15438 OCO Assessment of Need Report Interactive.pdf](#)

Furthermore, the Ombudsman's office was experiencing a marked increase in complaints relating to AON, with 95 parents going through their complaints process in relation to AONs between 2017 and 2019⁸.

Responding to this situation, the HSE developed a new model, which it proposed would standardise the process, leading to better access to interventions. The new model would entail a new Standard Operating Procedure (SOP) and include a less comprehensive Preliminary Team Assessment (PTA). However, alarm bells were sounded from many quarters about elements of the proposed new SOP while it was in development and after it was launched.

In 2018, responding to concerns flagged by therapists and parents, the Health Committee held meetings with therapists, parents/advocates and HSE. It then published a report⁹ in 2019, flagging major concerns with the proposed new SOP including that:

- The intention of the Act was to have an AON completed within six months, but under the new SOP, only a preliminary team assessment will be completed within six months.
- The new PTA will move children from the AON waiting list, which has a statutory time-frame under the Disability Act, to another waiting list which does not have a statutory time-frame.
- Stakeholders are unsure as to the evidential benefits of the PTA as it will not provide an effective assessment of a child's needs.
- Stakeholders are also concerned that the process is simply an attempt to reorganise waiting lists to fit in with statutory timeframes.
- The proposed SOP does not give a right of access to a diagnosis. It is proposed that diagnostic assessments, for example autistic spectrum disorder, will no longer be provided as a part of the AON protocol and will instead be identified as "health needs" in the service statement.
- On various occasions, the independent disability appeals officer has found against the HSE for failing to provide a comprehensive assessment of need,

⁸ As above

⁹ Health Committee report available [here](#)

including failures to address the specific concerns of the applicant in relation to the diagnostic assessment, as required by HIQA standards.

- The procedure places a number of professionals in breach of their own code of professional conduct. Such codes include the PSI code of ethics¹⁰ and the CORU framework for a common code of professional conduct and ethics of 2010¹¹.
- The PTA model is contrary to the Disability Act 2005 which was developed as a rights-based legislation. Prior to the SOP the child's needs determined the level and type of assessment provided. The SOP replaces this with a uniform screening assessment, regardless of the child's needs.
- The Committee is concerned of the lack of consultation between the HSE and stakeholders. The Committee welcomes the HSE's commitment, given during the meetings, that it will commence further consultation with stakeholders. In addition, the Committee recommends that such communication should be ongoing.

The 2019 Health Committee report recommended that that the new SOP should not brought into use before consultation with front-line therapists and parents.

The HSE implemented the new SOP in January 2020.

During 2020, warnings over the potentially problematic new SOP continued. A group of consultant paediatricians from Children's Health Ireland expressed concerns, writing in the Irish Times:

"The correct response to this crisis in providing timely intervention to children is to adequately resource a system which has been chronically neglected, and to employ expert staff in sufficient numbers to meet the needs of the population¹²".

¹⁰ [Code of Ethics | Article | PSI \(psychologicalsociety.ie\)](#)

¹¹ [framework-for-a-code-of-professional-conduct-and-ethics.pdf \(coru.ie\)](#)

¹² [Children and neurodisability – time to act – The Irish Times](#)

This followed a similar intervention by a group of GP colleagues¹³.

In October 2020 the Ombudsman for Children published ‘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 needs¹⁴’. This report raised serious concerns about ongoing violations of the rights of children with disabilities and echoed some of the issues that had been raised via the Health Committee in 2018 and 2019.

Given the child-centred, rights-based approach that report took and the serious issues it raised, the Committee decided to hold a series of meetings with stakeholders on it, to further examine the issues. As its first significant inquiry, the Committee hoped that there would be the potential to find solutions for the thousands of parents, children and professionals touched by these issues.

On 1 December 2020 the Ombudsman came before the Committee to discuss the report. At that point 6058 children were overdue an assessment. The understanding among Committee Members and the stakeholders they engaged with was that the PTA was limited to a 90-minute assessment.

On 8 December 2020 the Committee heard from therapists, representative bodies, parents and children’s rights solicitor Gareth Noble. The same concerns that were raised in 2018 were expressed again. Stakeholders were concerned that the SOP was being implemented without regard for the Health Committee’s recommendations and to the detriment of children. One witness told the Committee “the primary goal of the new SOP would appear to be solely to enable the HSE to meet its statutory obligations under the Disability Act¹⁵”. Another said “it has in effect sought to kick the can down the road in the proper assessment of children in a blatant and cynical way¹⁶.”

There were calls from some for its immediate cessation, with Mark Smyth, President of the Psychological Society of Ireland, stating:

¹³ The letter referenced a similar intervention by GP group GPs at the Deep End [Deep End Ireland – General Practice at the Deep End](#)

¹⁴ [15438 OCO Assessment of Need Report Interactive.pdf](#)

¹⁵ Mark Smyth, President of PSI, during meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

¹⁶ Solicitor Gareth Noble during meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

“The Psychological Society of Ireland, the Association of Occupational Therapists of Ireland and the Irish Association of Speech and Language Therapists seek the support of the committee in recommending an immediate cessation of the SOP¹⁷”.

On 15 December 2020 the Committee secured an agreement by Minister Rabbitte to review the SOP on the condition that the Committee hear from a number of specific HSE staff involved in its roll-out, in order for the analysis to be complete and well-rounded. Minister Rabbitte complimented the work of the Ombudsman and the Committee in highlighting the issues. When asked about whether the new SOP was motivated by a desire to move children from list-to-list to avoid litigation and appear to meet its statutory obligations, the Minister stated:

“The Senator made a valid point, asking if it came in just to save the State a fortune not to end up in court cases. It is part and parcel of it and I will not deny that. It is important to qualify it by saying that the HSE sought legal advice on it. When the HSE is before the committee, it is important and integral to ask if it was about the legal bill or about delivering a standard of intervention at the same level across the country. Was it part of putting a tool in place that every clinician could work to?¹⁸”

It is worth noting that 866 therapists working in disability services, who would otherwise be providing assessments and interventions, had been reassigned to covid swabbing and test and trace work for a period. In December 2020, 189 therapists had still not been returned to post, even though disability had been deemed an ‘essential service’ in September¹⁹. This had left a gap of seriously experienced and qualified individuals not being available to children.

On 2 March 2021, the Committee met with the HSE disability leads that Minister Rabbitte had recommended. They gave assurances that:

¹⁷ Mark Smyth, President of PSI, during meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

¹⁸ Minister Rabbitte, during meeting of 15 December 2020. Available at: [main.pdf \(oireachtas.ie\)](#)

¹⁹ For more on this see transcript of 15 December 2020. Available at: [main.pdf \(oireachtas.ie\)](#)

- The new SOP was not just about meeting the HSE's obligations within the Disability Act, 2005.
- Difficulties being experienced would resolve as the Progressing Disability Services programme progressed.
- All Children's Disability Network Teams would be fully configured in by the end of quarter two of 2021.

The following are two extracts from that meeting:

"The SOP needs to be understood in the context of the wider reform initiative we are implementing. I do not regard it as a defensive approach. I regard it as a mechanism by which we meet the law of the land. There are legal requirements for the State on assessment of need. However, in policy terms, if one looks at progressive disability services, in the UN convention ... assessment in and of itself without an interdisciplinary intervention programme is meaningless ... parents are waiting and crying out for intervention. The additional resources to clear the backlog allow the network teams that are being set up as we speak and that will be fully in place by the end of this quarter, quarter 2." – HSE Witness

"We will have all of our children's disability network teams *in situ* by the end of quarter two of this year, and that is where all the interventions happen."
– HSE Witness

The HSE confirmed that a year-long review of the new SOP would commence in March, with interim reports being made available after three and six months.

Major gaps in the HSE's ICT systems were a cause for concern among Members. 14 months after the new SOPs implementation, it appeared the HSE's database for assessment of need could not provide figures around how many children who had their initial assessment had been diagnosed or received intervention and how many were put onto other waiting lists²⁰.

²⁰ For more on this see transcript of 2 March 2023. Available at: [main.pdf \(oireachtas.ie\)](https://www.oireachtas.ie/main/pdf/oireachtas.ie)

The HSE clarified that, contrary to what had been widely discussed among stakeholders up to that point, the figure of 90 minutes for the preliminary team assessments – the shorter assessments under the new SOP – was a guide and every clinician uses their own clinical judgment to determine what is needed for a particular child.

On 11 May 2021 Minister Rabbitte again came before the Committee. At that point the number of children on the waiting list for an initial assessment was down to 1510 and some CHOs had completely cleared their waitlists²¹. Crucially though, the vast majority were assessed using the new SOP and the national average time it took to for a child to get an AON in the last quarter of 2020 was still about 19 months, which the Minister agreed was far too long to wait for crucial services. She said that contrary to previous statements, the 90-minute limit for clinicians was a guide. This was questioned by Members who said that the actual procedures guideline document still stated it was limited to 90 minutes. She also informed the Committee that she had asked the HSE to pause the relocation of existing special school-based services to try to ease some of the problems with staff being moved under Progressing Disability Service reconfiguration. She welcomed the appointment of Mr. Robbie Ryan to chair the review of the SOP.

In March 2022 a High Court judgment found that the Preliminary Team Assessment (PTA) approach under the new Standard Operating Procedure (SOP) for Assessment of Need (AON), did not fulfil the requirements of the Disability Act 2005.

Some key extracts from the judgment read:

“The AON is integral to the identification of need by the State in the discharge of its duties to vindicate and respect the rights of children with disabilities. It is only through the identification of need that the State is then equipped to measure the resources required to meet those needs and to deploy those resources”

²¹ That was the figure at end April, discussed in the Committee meeting on 11 May.

“The respondent has impermissibly sought through the introduction of the SOP to alter what is required under a Part 2 assessment by directing the conduct of assessments on the basis that all that is required under Part 2 is a preliminary team assessment of up to 90 minutes from which a “broad” statement of the nature and extent of needs may be discerned without requirement for diagnostic assessments²².”

No interim reports on the review of the SOP had yet been made available, in line with previous commitments.

On 6 April 2022, a government press release was published. In it, Minister Rabbitte said²³:

- As an interim measure, the HSE confirmed it is reverting to the pre- January 2020 process pending development of a new SOP.
- The HSE has established a group to develop, implement and oversee the changes now required to the AON service.
- Communication with and for families must be a key focus for the HSE and the Minister has reminded them of this a number of times.

Ten days later, on 22 March 2022, the HSE and Ombudsman appeared before the Committee. The Ombudsman said he concurred completely with the judgment and noted that reports arising from the review of the SOP were not delivered as promised. He also flagged that the implementation of the SOP was still in the HSE’s Service Plan for 2022, stating:

“In my view, however, in light of the High Court judgment delivered on 11 March, the review of the SOP is now redundant and continued implementation of the procedure is untenable²⁴.”

²² High Court Judicial Review [Record No. 2021/405 JR] [pdf \(courts.ie\)](https://courts.ie/)

²³ [gov.ie - Minister Anne Rabbitte welcomes HSE clarity on the protocol for Assessment of Needs for children and young people \(www.gov.ie\)](https://www.gov.ie/en/news/2022-04/minister-anne-rabbitte-welcomes-hse-clarity-on-the-protocol-for-assessment-of-needs-for-children-and-young-people/)

²⁴ For more on this see transcript of 2 March 2023. Available at: [main.pdf \(oireachtas.ie\)](https://www.oireachtas.ie/en/media/2023/03/02/transcript-of-2-march-2023/)

The HSE highlighted pathways to services outside of the AON process and confirmed that there was still no Children's Disability Network Teams fully staffed, with an average vacancy rate of 25%.

Both the Ombudsman and Members cited recent data indicating a continued failure to provide services to many children in need. For example, Inclusion Ireland's parent experience survey about Progressing Disability Services, published on 10 March 2022, found that out of the 1,013 families who responded, 83% reported a lack of services as one of their top three issues²⁵.

The dedication of staff on the ground, NGOs in the sector and section 38 and 39 workers, despite all the recent challenges, was praised by the HSE and Members²⁶.

On 26 April 2022 it was reported in the media that Health Minister Stephen Donnelly had directly intervened to order the HSE to hold 'on-the-ground' meetings with Disabilities Minister Anne Rabbitte amid concerns about how services for children were being delivered²⁷. Minister Rabbitte reported that she had been blocked, at a very senior level within the HSE, from having one-on-one meetings with disability managers in each CHO. She had also previously been told she was getting "too much in the weeds". She acknowledged, to an extent, that there was a culture of obstructionism within the HSE²⁸. Taoiseach Micheál Martin reportedly said a full review of the Progressing Disabilities Services programme for children is required²⁹.

In early May the Committee wrote to the HSE expressing concerns about these claims and support for Minister Rabbitte. On 6 May 2022 there were protests in Dublin, Cork, and Wexford regarding Progressing Disability Services. Minister Rabbitte said she would commence a Progressing Disability Services audit³⁰. In late May 2022, the HSE replied to the Committee, stating that the development of a roadmap was being

²⁵ [PDS Services Report 2022 \(inclusionireland.ie\)](https://inclusionireland.ie/PDS-Services-Report-2022)

²⁶ Section 38 employees are classified as public servants, whereas section 39 employees are not. The HSE can block grant/grant-aid these

²⁷ [Stephen Donnelly orders HSE to hold 'on the ground' meetings with Disabilities Minister \(irishtimes.com\)](https://www.irishtimes.com/news/health/stephen-donnelly-orders-hse-to-hold-on-the-ground-meetings-with-disabilities-minister-1.4611111)

²⁸ Minister Rabbitte speaking on [The Hard Shoulder Highlights - GoLoud Player](https://www.youtube.com/watch?v=...)

²⁹ [Midwest Radio - HSE concedes to Minister Rabbitte's request for one-to-one monthly meetings with Disability Managers](https://www.rte.ie/news/2022/05/24/1000000-hse-concedes-to-minister-rabbitte-s-request-for-one-to-one-monthly-meetings-with-disability-managers/)

³⁰ [Anne Rabbitte: Massive disability investment not translating to services \(irishtimes.com\)](https://www.irishtimes.com/news/health/anne-rabbitte-massive-disability-investment-not-translating-to-services-1.4611111)

developed collaboratively with all stakeholders, to progress the next phase of implementing Progressing Disability Services.

On 2 June 2022, a joint meeting of the Committee and the Committee on Disability Matters, along with Minister Rabbitte, and representatives from the Department of Health was held. Minister Rabbitte told the Committee that, of the €7.8 million she initially secured to clear the backlog of 6000-6500 overdue AONs at the start of her term as Minister “importantly, these AONs were not completed using a preliminary team assessment, PTA.” She said approximately 10,000 AONs were completed while the new SOP with the PTA was in use and that now “in light of the recent High Court ruling, many of these will have to be redone”. At this point, the HSE was receiving approximately 6000 AON applications annually. Children’s Disability Network Teams, at this stage had a vacancy rate of 28%, up 3 percent from March. Recruitment was discussed at length and is discussed further in key issue 2. The HSE advocated strongly for a review of the Disability Act.

On 31 July 2022 Minister Rabbitte acknowledged that the disability sector was “in crisis” with regard to the assessment of children with special needs and the delivery of therapy services to them³¹.

On 12 September 2022, parents campaign organisation FUSS reported the Taoiseach Micheál Martin as having said that the Progressing Disability Services model had failed but having advised that the government were not ‘shirking their responsibility’ and would ‘follow through’ to ensure a functioning system was implemented³².

On 29 September 2022, during Leaders’ Questions on the subject of AONs, resources for disability and the primacy the current system places on diagnosis, the Tánaiste Leo Varadkar said it was perhaps time to consider a change of approach³³.

On 21 November 2022 it was widely reported that a High Court judge had ordered the HSE to appear in court regarding a “dramatic” increase in the number of actions over

³¹ [Fianna Fáil Minister Anne Rabbitte says disabilities is the ‘Cinderella’ within Department of Health – ‘We’re never the first thought’ - Independent.ie](#)

³² [Press Release: Meeting with the Taoiseach \(fussireland.com\)](#)

³³ [Ceisteanna ó Cheannairí - Leaders' Questions – Dáil Éireann \(33rd Dáil\) – Thursday, 29 Sep 2022 – Houses of the Oireachtas](#)

delays in processing applications for the assessment of children with special needs³⁴. The judge said there has recently been an average of seven new applications for judicial review on these issues per week³⁵.

On 5 December 2022 it was reported that the HSE has apologised to families after the number of children with a disability waiting for initial contact to access care rose to 18,000³⁶.

1. Resources and Capacity

“If there are long surgery lists, one hires more surgeons. One does not shorten the length of the surgery, offer fewer surgeries or ask someone else to do it. It is a case of insufficient resources³⁷. ”

That analogy, put by Mark Smyth, President of the Psychological Society of Ireland, in one of the Committee's first meetings on these issues, summarises much of what has gone wrong in children's disability services to date, including in terms of the new SOP. While the Committee is in favour of a SOP in theory, as are many therapists it engaged with, assessments and interventions are too important to be shortened or streamlined beyond a certain point. The Committee also heard that 91% of children do not receive their assessments within the timeframe prescribed and mandated by law.

Much has been made of the Disability Act's over-emphasis on diagnosis as opposed to recognition of need. Ultimately, parents would not be using the Act as a mechanism to force the HSE into providing services to their children if sufficient resources were available and their children's needs and rights were being met. While the Committee is in favour of a review of the Act, under certain specific conditions, its focus on the right to an assessment cannot be used as a scapegoat for the glaring failure to provide for children over many years. We need to properly resource disability services and deliver on the Act that is currently in place, before embarking on a review of it.

34 [Judge orders HSE to appear in court after 'dramatic' rise in Assessment of Need cases \(irishexaminer.com\)](http://irishexaminer.com)

35 As above

³⁶ [HSE apologises as 18,000 children with disabilities wait for first appointment \(irishtimes.com\)](https://www.irishtimes.com/news/health/hse-apologises-as-18-000-children-with-disabilities-wait-for-first-appointment-1.4644444)

³⁷ Mr. Mark Smyth during meeting of 8 December 2020. Available at: [main.pdf \(oireachtas.ie\)](#)

There seems to be a tendency to underfund services for the most vulnerable or expect therapists to perform miracles of the loaves and fishes variety, to deliver more amidst growing demand and limited resources. The Committee and stakeholders discussed a marked difference in services before versus after the austerity cuts imposed from around 2008 to 2011. The HSE itself acknowledged that austerity cuts during the last recession are still having an impact, particularly on the disability sector³⁸. That admission, that access to disability services has not only not improved, post-recession, but that it hasn't even recovered to pre-crash levels, is startling.

One Member told the Committee that he begged an ex-Taoiseach to prevent cuts being imposed on carers and people with disabilities in 2011, stating:

“He said he could not give me that undertaking. He told me this is a private matter between me and my son and that the State could not be expected to intervene meaningfully in the lives of persons with disabilities. That is the ideological imperative that has brought us to this space³⁹.”

Luckily, policy-makers now are generally united around common goals to try to better provide for people with AONs and their families and carer givers. There is clear political will, across the political spectrum, to intervene meaningfully in the lives of disabled people. Will, however, is not enough. Corresponding resources must be provided. High levels of spending do not necessarily equate to adequate spending if demand is also at an unprecedented level, and the sector is still suffering from legacy cuts.

While it seems crude to appeal to the potential financial savings to be made by the State if disability is sufficiently resourced, because the needs and rights of disabled children should be met without regard to cost, it is worth doing to ease concerns among more fiscally conservative decision-makers.

Under resourcing in the present tends to create higher costs in the future, in terms of legal fees and in terms of children requiring more intensive care. This was reflected in

³⁸ See transcript of 2 June 2022, for example, for more on this. Available at: [main.pdf \(oireachtas.ie\)](#)

³⁹ See Senator Clonan's contribution during meeting of 2 June 2022. Available here: [main.pdf \(oireachtas.ie\)](#)

the Health Committee report on the new SOP published in 2019, which identified resourcing as a fundamental problem, stating:

“At the heart of this issue is the fundamental problem of resources. The shortfall in staffing and other resources is injurious to the future health of children ... the Committee discussed the ‘golden window of opportunity’, a critical period of a child’s development during pre-school and early-school years. It is essential that assessments and services are provided for in this period. Rationing support services for children at an early developmental stage is likely to have a ripple effect that will require additional funding and support at a later stage, as well as having a knock-on effect with our educational services, our healthcare system and the child’s welfare.⁴⁰”

Ms. Justice Siobhán Phelan, the judge who made the ruling against the new SOP in the High Court on 11 March 2022, also expressed concern about a shortage of resources generally and the issue of resources having to be directed to the defence of litigation rather than the provision of services⁴¹. She quoted one of the HSE’s clinical leads in a report, which stated that the Disability Act puts clinicians in “an invidious position of having a legal obligation to assess needs without necessarily having the means to address them⁴²”. Not having the means to address children’s needs constitutes a lack of resources. There needs to be an acknowledgment of the levels of resourcing required at all levels politically and within the HSE, in order to address the crisis in the disability sector.

In his report ‘Unmet Needs’, the Ombudsman also concluded that the main cause of these waiting lists is “an insufficiency of resources allocated to meet the demand for AONs”. This is in keeping with the evidence the Committee heard from almost all stakeholders. There was a divergence between the way therapists, parents, and various expert witnesses addressed the issue of resources versus how senior HSE

⁴⁰ Health Committee report 2019. Available [here](#).

⁴¹ Para 172 in [pdf \(courts.ie\)](#)

⁴² Pg 15 [Towards equitable access to quality services for children and young people with disabilities in Ireland Mac MacLachlan 2019 Hilary \(maynoothuniversity.ie\)](#)

staff and some senior elected representatives did. This warrants exploring, in case it sheds any light on what might be preventing fixes in childrens' disability services.

In general, during the examination of these issues at Committee hearings, the HSE seemed reluctant to comment on a shortage of funding or resources. Mostly, when discussing the need for more resources, the HSE quickly referred back to those already provided. Take, for example, these five contrasting contributions from HSE and non-HSE witnesses:

HSE witness: "While acknowledging the very significant level of resources allocated to disability service provision, which was approximately €2.2 billion in 2021, planned multiannual investment coupled with reform of the sector is necessary in order to build and strengthen early intervention and the provision of family-centred supports⁴³."

Non-HSE witness: "I often find it strange how little we hear from the HSE about wanting additional funding to meet its obligations under the Disability Act for recruitment and so on. I recall being involved in one case a number of summers ago where it took longer than the six-month timeframe for a complaint to be heard. In that case, the HSE's solution to the backlogs was not to call for more recruitment of speech and language therapists, OTs, physiotherapists or psychologists. Instead, much to the bewilderment of the court, its priority was to beef up the complaints system.⁴⁴"

HSE witness: "It is not all about throwing money at the problem. Rather, it is a question of attracting graduates, filling posts and having suitably qualified and experienced staff available to provide supports for children and families.⁴⁵"

Non-HSE witness: "I disagree with the idea that money has been thrown at the problem. There has been underinvestment in health and social care professional services for many years. We understand the financial difficulties and the challenges within which the HSE is operating, and the impact of the recession ten years ago, but there has been

⁴³ Dr Cathal Morgan, Head of Operations with Disability Services, meeting of 2 March 2023. Available at: [main.pdf \(oireachtas.ie\)](#)

⁴⁴ Gareth Noble, Children's Rights Solicitor, meeting of 8 December 2020. Available at: [main.pdf \(oireachtas.ie\)](#)

⁴⁵ Angela O'Neill, National Disability Specialist, HSE. Meeting of 22 March 2022. Available at: [main.pdf \(oireachtas.ie\)](#)

historic, chronic under resourcing of health and social care professional services and that needs to be addressed⁴⁶.”

HSE witness: “Any fair analysis will show that a fairly substantial level of resources is being put in with regard to supports and services for children and adults with disabilities, with a record level of investment this year of €2.2 billion.⁴⁷”

This pattern is reflected in the comments of some senior elected representatives also. Health Minister Stephen Donnelly and Taoiseach Micheál Martin have both been recently reported as saying money is not the issue⁴⁸. Minister Rabbitte, however, has been more critical of resourcing and more in tune with the actual need for investment. For example, in the following extract from a media interview she describes disabilities spending:

“As the ‘Cinderella’ within the vast Department of Health, where its budget of €2.3bn is only a tenth of the €23bn spent annually on the health service. ‘We’re always that second or third thought,’ she says. ‘We’re never the first thought.’ Part of the problem, she argues, is the vast majority of her budget is taken up with paying for existing services. More than €1.5bn is spent on residential care, with €500m going on day services. Only 3pc of the overall disabilities budget is spent on the delivery of therapies for children. ‘When you look at the amount of children that need access to therapies and to think that it’s only a sliver of the budget, sure it’s totally imbalanced,’ she says”⁴⁹.

⁴⁶ Odhrán Allen, Chief Strategy Officer with the Association of Occupational Therapists of Ireland, meeting of 8 December. Available here: [main.pdf \(oireachtas.ie\)](#)

⁴⁷ Dr Cathal Morgan, Head of Operations with Disability Services, HSE, meeting of 2 March 2023. Available at: [main.pdf \(oireachtas.ie\)](#)

⁴⁸ [Cork Fianna Fáil TD criticises HSE for ‘litany of mistakes’ \(echolive.ie\)](#) and [Boy with ‘profound’ autism waiting two years for reassessment despite recommendation to three HSE managers – The Irish Times](#)

⁴⁹ 31 July 2022: Anne Rabbitte in The Sunday Independent. [Fianna Fáil Minister Anne Rabbitte says disabilities is the ‘Cinderella’ within Department of Health – ‘We’re never the first thought’ - Independent.ie](#)

It is important to consider what the actual allocations to particular elements of disability are and what factors contribute to the impression that resources are in plentiful supply, when a majority of stakeholders the Committee engaged with say they are not. On the one hand, the Committee heard of parents at risk of losing their homes in their fight for services. On the other hand, much was made of the €350 million allocated for waiting lists in 2022, for example. During the Committee meeting on 22 March 2022, after prolonged questioning of the HSE about how much of that would actually go towards disability waiting lists, it emerged that there is €20 million from the €350 million allocated in total for the community waiting lists, and that disability will receive “an element of that”. The HSE did not know yet, at that stage, what portion of the €20 million would be allocated to disability⁵⁰.

Speaking to the Committee in March 2022, the HSE discussed the disability capacity review⁵¹, which identified that €1.1 billion is required to meet the current level of demand. While recent efforts to increase disability spending are welcome, gains in budget 2023 do not reflect the level of resources that the disability capacity review identified as essential, nor the input required to finally overcome legacy austerity cuts while providing for increasing demand⁵². An Action Plan is to be published, to accompany the capacity review. This should be published as a priority, with ambitious targets, to be met with equally high levels of funding. In the next section we explore how funding might be harnessed to better address recruitment and retention, which all stakeholders agree is one of the biggest challenges in disability services.

The Committee recommends that:

1. The disability capacity review action plan should be rights based and UNCRPD compliant and should be published immediately.
2. The Budget 2023 allocation should be increased significantly to ensure the provision of adequate financial, technical, and human resources for disability services to meet

⁵⁰ For more on this see transcript of meeting of 22 March 2022. Available at: [main.pdf \(oireachtas.ie\)](#)

⁵¹ Disability Capacity Review available here. [154163_8fe32ca7-2154-4fb0-8a41-6931c5f15471.pdf](#)

⁵² A breakdown of the key allocations is available in a budget statement by Minister Rabbitte [here](#)

the investment targets set out in the Disability Capacity Review and to improve the timeliness of AONs.

3. The legacy impacts of austerity cuts must be curtailed and remedied as a matter of urgency.

4. There needs to be an acknowledgment of the levels of resourcing required at all levels politically and within the HSE, in order to address the crisis in the disability sector.

2. Recruitment and retention

This section looks at how finance can be used to attract personnel, the urgent need to reform the panel system and some other immediate actions that can be taken to improve retention, including measures to support more graduates.

One immediately implementable action would be for the HSE to conduct and analyse exit interviews with staff leaving the sector. In the June 2022 meeting, the HSE were asked about exit interviews. The HSE said they hoped to have a system for exit interviews in place within weeks. One Member described it as “as a simple way to resolve things, it should have been done a long time ago⁵³”. The Committee then asked, through a request for follow-up information in November 2022, if exit interviews were now taking place with staff leaving the sector as standard practice, whether these yet been used or analysed, and for information on any insights gained. The Department advised that the HSE stated that “National Disability Operations have requested that CHO Areas undertake exit interviews to establish the reasons why staff are exiting services”. This should be implemented, not requested, as a priority. It is established best-practice where there are challenges around staff retention and valuable lessons may be learned.

⁵³ Deputy Mark Ward during meeting of 2 June 2022. Available at: [main.pdf \(oireachtas.ie\)](#)

Translating funding into personnel

Resources and recruitment and retention are two sides of the same coin in many respects, and while the HSE seemed reluctant to discuss financial under-resourcing during its discussions with the Committee, it has always been forthright during discussions on the shortage of human resources, i.e., personnel such as therapists. However, financial resources have not been mobilised successfully to alleviate recruitment and retention issues in children's disability services. The potential to use the finance to attract the personnel must be harnessed.

On 23 November 2022, Taoiseach Micheál Martin was reported as having said that the problem is at a scale it should never have reached “and it's not a funding issue”. He stressed that salaries and conditions are not problems because recruitment and retention of therapists in other areas of the health service is not an issue⁵⁴. He stated that he had arranged two meetings with all the Ministers responsible for special needs to deal with this issue, saying “we have to develop more accelerated means to assess needs, but the key issue is recruitment of a sufficient number of therapists to provide not just assessment, but interventions for children who require them⁵⁵.”

While the Taoiseach's appetite to address the issue is very welcome, as are the meetings he arranged, his interpretation of the recruitment issues is at odds with much of the testimony the Committee heard. Many witnesses the Committee has engaged with refer to major issues in recruitment and retention across the board within the health and social care professions. The HSE informed the Committee in June that it needs to recruit 9500 people every year just to stand still, i.e. to break even in terms of staffing levels⁵⁶. In late September 2022, the Secretary General at the Department of Health put this figure at 10,000⁵⁷. One Member informed the Committee that 75% of medical graduates plan to leave Ireland⁵⁸. Salaries and conditions are considered major problems by many, and, if lack of funding is not an

⁵⁴ [Boy with 'profound' autism waiting two years for reassessment despite recommendation to three HSE managers – The Irish Times](#)

⁵⁵ As above

⁵⁶ See transcript of 2 June 2022 for more on this. Available at: [main.pdf \(oireachtas.ie\)](#)

⁵⁷ [Health chief admits 'failure' to deal with exit of graduate medics from Ireland – The Irish Times](#)

⁵⁸ Senator Tom Clonan quoting Dr Ray Walley during meeting of 2 June 2022. Available at: [main.pdf \(oireachtas.ie\)](#)

issue, then there is a clear impetus to increase salaries. If a recruiter cannot attract the talent required on the salary they are offering, then they generally put the wages up. The state, through the HSE must do the same, for essential front-line workers, including therapists.

The Committee heard calls for pay equality to be restored and for pay and conditions for Section 39 workers to be improved, on a long-term basis, not through once-off funding, to ensure they are on par with their HSE counterparts. While a recent commitment to block grants for these groups is welcome as an interim measure, it is a short term and limited solution⁵⁹. The Labour Party tabled a motion to this affect in October 2022 which the Government did not oppose. In fact, Health Minister Stephen Donnelly thanked Labour T.D. Duncan Smith for bringing forward the “important” motion⁶⁰. The Committee are also in favour of pay equality for Section 39 workers.

There have been many analyses of the so-called medical ‘brain drain’ and crisis in health and social care in Ireland over the last two decades⁶¹. Some of these look at hours, pay and tax; three things that have often been deemed not to be up for negotiation in the past. The Covid-19 pandemic showed, however, that in an emergency, with political will and the appropriate resources, the State can work in unusual ways. The disability sector is in crisis and crisis thinking needs to be employed to enable changes that wouldn’t be implemented in non-emergency times. Changes in hours, pay and tax should be implemented to recruit and retain workers in the sector.

Further education, trainees and international candidates

The Committee discussed cases of student therapists receiving no remuneration for their internship or placement work. That must be remedied immediately. Potential incentives and measures were discussed at the joint meeting with the Committee on Disability Matters⁶². Special grants towards fees and costs associated with training for

⁵⁹ See [Government grants made available to boost pay for section 39 workers \(irishtimes.com\)](https://www.irishtimes.com/news/health/government-grants-made-available-to-boost-pay-for-section-39-workers-1.4644444) for more on this

⁶⁰ [Govt will not oppose healthcare pay rise motion \(rte.ie\)](https://www.rte.ie/news/health/2022/10/20/healthcare-pay-rise-motion/)

⁶¹ See for example [Doctor Retention: A Cross-sectional Study of How Ireland Has Been Losing the Battle \(ijhpm.com\)](https://www.ijhpm.com/doctor-retention-a-cross-sectional-study-of-how-ireland-has-been-losing-the-battle/) and [RCSI Layout First Section \(2013\) 2 RCSI \(rcsismj.com\)](https://www.rcsi.ie/2013/02/20/rcsi-layout-first-section-2013-2/) in relation to doctors, for example

⁶² For more on that Joint Committee meeting see transcript, available here: [main.pdf \(oireachtas.ie\)](https://www.oireachtas.ie/committees/disability-matters/main.pdf)

therapists should be established. Furthermore, many professions train staff but then require a certain length of service from them in return. Consideration should be given to building in a mandatory term of service in Ireland for those that train here.

The HSE told the Committee that graduate entry programmes in other countries in areas such as speech and language therapy and occupational therapy only take two years, that the HSE want to see increases in health and social care at third level⁶³. Minister Rabbitte told the Committee in 2020 that she was “meeting the Minister for Further and Higher Education, Research, Innovation and Science, Deputy Harris, with a focus on the CAO offers perhaps providing additional availability to help address some of my unmet need in the disability sector⁶⁴”. In relation to producing enough graduates, the HSE told the Committee that this would take a number of years. The HSE also told the Committee that it is important to be honest about the capacity of the system to change in a particular timeframe and that they “have to start work on it immediately.” It is a cause for concern that we are still talking about starting work on these issues. They should have been tackled long ago, given the longstanding availability of data around the increasing demand for services and the lack of therapists.

Then Minister for Higher Education, Simon Harris, was quoted in September as having said he would be “happy to extend places in third level if [he] gets figures from the Department [of Health] or the HSE⁶⁵”. Why, if this solution has been on all stakeholders’ radars for so long, has it not been actioned? Commenting on this need in March the Ombudsman said “we are asking what we can push the Government to give the HSE and what is clearly needed, whether that includes further education, more courses, classes, recruitment, senior posts and whatever else.” The Committee echoes this call. The time for looking at these fixes is long past. They need to be urgently implemented.

In correspondence to Committee dated November 2022, the Department stated that data for the 2022 Children’s Disability Network Teams Staff Census and Workforce

⁶³ Professor Malcolm MacLachlan, HSE, during meeting of 22 March 2022. Available at: [main.pdf \(oireachtas.ie\)](#)

⁶⁴ Minister Rabbitte, during meeting of 15 December 2020. Available at: [main.pdf \(oireachtas.ie\)](#)

⁶⁵ [Health chief admits ‘failure’ to deal with exit of graduate medics from Ireland – The Irish Times](#)

Review is currently being collated. While this is welcome it now needs to be urgently progressed.

The Committee was also informed that options to support the recruitment of staff for the Children's Disability Network Teams 'currently being explored' include:

- Targeted National Recruitment for CDNTs
- Targeted International Recruitment for CDNTs with an agreed relocation allowance
- Sponsorship Programme for therapy grades
- Apprentice Programme for therapy grades
- Employment of graduates as therapy assistants as they await CORU registration
- Expansion of therapy assistants in the system with HSE supporting individuals to return to education to qualify as therapists.

While these measures are welcome, the Committee is again concerned that at the time of reply they were only 'being explored'.

In relation to international recruitment, the Department informed the Committee that the HSE has approved an attractive and competitive relocation package for the international recruitment of all disciplines. This is welcome and should be capitalised on. The HSE also report that pre-clearance and serving notice to current employers can delay the process, both by a number of weeks. In the context of the timelines for other initiatives discussed in this section, a number of weeks is short. Initiatives related to hiring internationally must be implemented and capitalised on urgently, including the relocation allowance.

The panel system

The panel system of recruitment used by the HSE entails vacancies being filled according to the order of successful candidate's placement in terms of points scored, rather than other factors, such as the specific need to fill a particular position or with regard to geography. Members described it as cumbersome and expressed frustration

that the HSE cannot recruit locally. As one witness said “it does not get the right staff into the right place⁶⁶”.

During the meeting of 8 December 2020, the Committee were told the following by witnesses representing the Psychological Society of Ireland, the Association of Occupational Therapists of Ireland and the Irish Association of Speech and Language Therapists:

“We know the process does not work, and we have been saying for ten years that we need to be listened to in order that we can get these people in place and ensure that children have their needs met.”

“Our professional bodies, on behalf of all the health and social care professionals, released a report last week on the HSE’s national panel system of recruitment. Among all the HSCPs that responded - more than 1,200 - 92% suggested that the current panel-based system of recruitment was not fit for purpose. Despite the Government over the past ten years noting a recruitment and retention issue in respect of health and social care professionals who are required on the ground to deliver these services, its own method of recruitment is one of the greatest barriers to getting staff in place⁶⁷.”

In correspondence received from the Department in November 2022, the Committee was advised that there are panels in place for occupational therapists, psychologists, physiotherapists, speech and language therapists and that these panels will be expanded further that month. If, as the witnesses that came before the Committee state, the panels have not been fit for purpose and this has been known for over a decade, why has this not been addressed? The Committee is concerned that this may be a significant contributor to recruitment issues and recommends the replacement of the current panel-based system of recruitment with a new system developed in

⁶⁶ Mark Smyth, President of PSI, during meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

⁶⁷ Mark Smyth, President of PSI, during meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

conjunction with health and social care professionals. This should not impact on or pause hiring in the meantime.

The Committee recommends that:

5. The terms and conditions for Section 39 workers are made equal to those of their public service counterparts.

6. Wages for therapists should be increased, hours should be decreased (while retaining optional overtime) and tax breaks/incentives should be created for those working in the sector.

7. Student therapists must receive remuneration for their internship and placement work.

8. Special grants towards fees and costs associated with training for therapists should be established (in addition to the universal SUSI grant application process).

9. Working conditions within the disability sector must be improved.

10. The Department and HSE should ensure that exit interviews are conducted with all HSE staff who leave the service and improve working conditions based on insights from these.

11. The recruitment process for hiring staff involved in providing interventions and assessments must be reformed to ensure a quicker, more efficient system.

12. The panel-based system of recruitment should be replaced with a new system, which should be developed by working in conjunction with health and social care professionals. This should not impact on or pause hiring in the meantime.

13. 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.

14. The options to support the recruitment of staff for the Children's Disability Network Teams currently being explored by the HSE need to be actioned, resourced and implemented now.

15. There must be an immediate increase in health and social care places at third level and engagement at all years of the course with the HSE and CDNTs to foster atmosphere of ownership of progression to employment in these networks.
16. Shorter college courses for therapists should be developed, and insights should be drawn from other countries, where, in areas such as speech and language therapy and occupational therapy only take two years
17. Initiatives related to hiring internationally must be implemented and capitalised on, including the relocation allowance.
18. Consideration should be given to building in a mandatory term of service in Ireland for those that train here.

3. Systems and Organisation

“I know from meeting parents and visiting services themselves that frontline staff, whether clinicians, day service staff, respite and residential staff and so on, are doing their best to deliver services and support people accessing the service. The issues often lay elsewhere in the system.” – Minister Anne Rabbitte⁶⁸.

The HSE has not met any of the proposed deadlines for any of the actions it told the Committee it was taking to resolve the problems associated with AONs and interventions for children. Interim reports on the review of the SOP were not delivered. Children’s Disability Network Teams have an average vacancy rate of 28%. In November 2022, the much-needed new ICT system had still not been delivered. Nine months on from the High Court judgment the Committee asked for details on the new plan for a SOP and received a reply stating that interim clinical guidance was being developed and would be finalised shortly, and that, following legal advice on the

⁶⁸ [Anne Rabbitte: Massive disability investment not translating to services \(irishtimes.com\)](https://www.irishtimes.com/news/health/anne-rabbitte-massive-disability-investment-not-translating-to-services-1.6444444)

interim guidance, further information would be provided to service users and service providers.

In 2020, the Committee took the HSE in good faith regarding the new SOP and other measures and allowed for time for these to bed in. Years into what was intended as reform of the system, we are, arguably, much worse off. As discussed, a large proportion of the ten thousand assessments carried out using the new SOP will likely have to be repeated and data the Department provided to the Committee in November 2022 showed the number of other overdue AONs at 4685. As detailed in the background section, there seemed to be a disconnect between the information Minister Rabbitte and the HSE provided at times.

All of this raises some difficult issues for the Committee in considering potential recommendations. The failures within disability services over the last number of years have caused immeasurable harm to children, parents and therapists.

It is only fair to acknowledge that the Department and HSE faced many challenges related to the Covid-19 pandemic. In addition, the HSE has provided a certain amount of data to the Committee and has never responded in the negative when asked to come before it. The HSE also met with the Ombudsman and provided information to support the development of his report on the issues. The Committee also acknowledges that more funding has now been secured to tackle waiting lists for AONs and admires the hard work of many within the HSE.

Efforts to reorient disability within the system have also been hampered. Following the reconfiguration of Departments after the last election, specialist disability services was to transfer from to the Department of Health to the new Department of Children, Equality, Disability, Integration and Youth. This has still not taken place, years on since the formation of the Government and has potentially caused problems in terms of clarity of roles and responsibilities and accountability. Minister Rabbitte herself has

spoken of “being obstructed” by the HSE⁶⁹ and said that “disability is a rights issue, and it should sit inside the Equality department⁷⁰”.

There are avenues for improvements in the systems and organisational structures that should be pursued, such as the roadmap that was to be available in June 2022, the audit of Progressing Disability Services and so on. The Committee is aware that there have been issues with unions and representative organisations and the HSE, but these must be overcome, and agreements reached. Joined up thinking and effective collaboration will be essential to fixing this system.

The Committee recommends that:

19. A clear plan must be communicated to parents regarding the situation with AONs going forward, including timelines and information on what measures are being taken, budgetary and otherwise, to get children the services they need.

20. The audit of Progressing Disability Services must begin now and report back in quarter one of 2023. Independent experts must be involved. It should report to the Minister of State for Disability, the Minister for Health, an Taoiseach and the Committee on Children, Equality, Disability, Integration and Youth simultaneously.

21. Responsibility for delivery of essential services for disabled Children should lie jointly with the Department of Health, Department of Children, Equality, Disability, Integration and Youth *and* the Department of the Taoiseach until such a time when the backlogs are cleared and confidence is restored.

22. The Roadmap, that was to be made available in June, must be progressed and should be published by end February 2023.

23. A central ICT database should be created that collects AON data in order to identify problems, assess progress in strategy implementation, and inform national policy

⁶⁹ Minister Rabbitte speaking on [The Hard Shoulder Highlights - GoLoud Player](#)

⁷⁰ [Rabbitte vows to cut delay that disabled people face acquiring necessary aids and appliances \(irishexaminer.com\)](#)

development. The Committee on Children, Equality, Disability, Integration and Youth should be pro-actively updated with data on how AON and PDS figures are progressing, on a monthly basis, in the way that others Oireachtas Committees are updated on key metrics under their remit. The new ICT system must be successfully implemented within the HSE as a matter of urgency.

24. The work of the Interdepartmental Group on Children with Disabilities, which includes members from the Departments of Health, Education and Children, Disability, Equality, Integration and Youth, as well as associated agencies, must be intensified and that group should be facilitated to have more of an impact in terms of resolving the issues identified in this report.

4. The Assessment

The HSE informed the Committee that, although a range of guidance notes relating to the assessment of need processes were issued from 2007, there was no nationally standardised or agreed operational approach or definition of an assessment of need. Various reports over the last decade have found significant variation in the way assessments were conducted across teams and areas.

The National Disability Authority's 2011 report found that:

"It does not appear that clinicians are forced by the requirements of the Disability Act 2005 to conduct more comprehensive assessments. It is the case that a statutory assessment of need has to happen within a much shorter timeframe than other similar assessments, which assessors said, has the effect of causing other work to be pushed back.⁷¹"

This is instructive in two respects. Firstly, it again illustrates why the statutory AON process is increasingly used by those seeking access to services and supports. It is, in the context of the competition for services that children and parents face, seen as a

⁷¹ [National Disability Authority Report on the Practice of Assessment of Need under Part 2 of the Disability Act 2005 - National Disability Authority \(nda.ie\)](#)

stronger route to accessing services because of the statutory timelines in the Act. Secondly, it shows that excessively comprehensive assessments are generally not the problem. The lack of resources is the problem, causing other work – that which does not have statutory timelines for completion – such as the delivery of interventions, to be pushed back. Shortening the duration of assessments then, is not the primary solution. Providing enough resources to provide both assessments and interventions is.

The Committee did hear of some cases where assessments were excessively long. The figure of 100 hours was quoted as the upper limit of the time taken to do one assessment in one area, but that was an exceptional outlier. Increasing consistency and efficiency in the AON process should be progressed, but in tandem with essential increases in resources, both in terms of personnel and finance.

The Psychological Society of Ireland told the Committee:

“Adequate time with parents or guardians and the child is required for the purposes of direct assessment. It is also essential to give parents or guardians time at the conclusion of an assessment to process their reactions to any diagnosis or other feedback”⁷².

Therapists the Committee engaged with are theoretically supportive of a SOP, once it is designed with the child’s best interests front and centre, and in compliance with the relevant Acts and standards or professional codes. Appropriate tools, guidance and supports should be provided for assessment officers and all those working in disability services generally. Appropriate informational materials and guides on the AON process should be provided for both parents and children as well.

The Committee heard in 2021 that the HSE had established a new National Clinical Programme for People with Disability, which is supporting clinicians in carrying out their work and directly involves people with lived experience in the design of clinical assessment and interventions⁷³. Efforts were under way in terms of assessment of

⁷² Meeting of 8 December 2020. Available at [main.pdf \(oireachtas.ie\)](#)

⁷³ See transcript of 2 March 2021 for more on the National Clinical Programme. Available at: [main.pdf \(oireachtas.ie\)](#)

autism, which now forms part of a dedicated service improvement programme aimed at developing supports and services for the autistic community.

These initiatives, intended to alleviate the current situation in relation to AONs and interventions, are welcome, as is the inclusion of clinicians with relevant experience. However, the need for disabled people themselves to be represented in these forums cannot be underestimated. It is essential. Service users generally, including parents and carers, must be represented and allowed to provide substantive input. Minister Rabbitte confirmed in a parliamentary question of 8 November 2022 that the National Clinical Programme for People with Disability has led the process of developing Interim Clinical Guidance to replace the element of the SOP which was found to be non-compliant with the Disability Act. It is hoped this process involved all of the stakeholders mentioned.

A document on the Governance Structure and Function of the National Clinical Programme for People with Disabilities states that disability-stakeholders, including service-users are part of the programme:

“These stakeholder views are represented as permanent positions on the DAG; with representative organisations making nominations for people to provide their relevant perspective. This nominee will not be representing any specific organisation, but rather providing a distinctive perspective. The perspectives required will be from service providers (Section 38 & 39), an umbrella civil society organisation, a carers association; a community association, family members and direct service users. The representative groups will therefore have 7 members in total on the group⁷⁴.”

This is welcome. A call for expressions of interest from people with lived experience of having a disability to be part of the programme states:

“The task group is recruiting 3 people with lived experience of disability. We would like a range of people, ideally somebody with an intellectual disability,

⁷⁴ [clinical-programme-for-disability-governance-structure-and-function.pdf \(hse.ie\)](https://www.hse.ie/eng/yourhealth/mentalwellbeing/clinical-programme-for-disability-governance-structure-and-function.pdf)

somebody with a physical, sensory or other type of disability and somebody who is a family member or carer to a person who uses disability services.⁷⁵

The Progressing Disability Services audit should look at how the programme is working, including analysing how many people with lived experience of having a disability are actively involved, whether that amount is enough, and whether they are being enabled to provide meaningful input into the programme's work. The programme involves many different actors. It is important that the input of disabled people, parents and carers is central and their voices are not drowned out.

Following a legal judgment in 2021, if a HSE Assessment Officer forms the opinion that there may be a need for an education service to be provided, the National Council for Special Education (NCSE) now has the responsibility to nominate an appropriate person to carry out an assessment of education needs on behalf of the HSE under the AON process. In October 2022 an information note on new arrangements to be implemented in schools on foot of the 2021 ruling was sent to all schools. In it, the National Council for Special Education appears to nominate the school principal as the appropriate person to carry out at least part of an assessment of education needs on behalf of the HSE.

Section 4 of the information note reads:

“Completion of the Report of Education Needs for the Purpose of Assessment of Need:

If requested to assist the HSE in the AON process, the NCSE will forward to the school/nominated person a form titled '*Report of Education Needs for the purpose of Assessment of Needs (Disability Act 2005)*'.

If forwarded to a school for completion, this form should be completed by the school principal, or a teacher nominated by the school principal who is familiar with the student (e.g., Class/Subject Teacher, Special Education Teacher).

⁷⁵ [161650317597891.pdf \(disability-federation.ie\)](#)

The NCSE will specify the date whereby a school/nominated person, is obliged to return the Report of Education Needs for the purpose of Assessment of Needs (Disability Act 2005). Since this is a statutory process, there is a requirement for schools/nominated person to return the form to the NCSE within this stated time frame.⁷⁶

This sparked some controversy among teachers and principals, with many saying that they are not qualified to assess special educational needs. In an exchange in the Dáil during topical issues, Minister of State Dara Calleary said that “where the child is enrolled in a school the Education of Persons with Special Education Needs Act 2004 names the principal as the person the NCSE should contact⁷⁷.” Deputy Donnchadh Ó Laoghaire, Sinn Féin Spokesperson Education and Skills said that it is educational psychologists who should be doing this work.

Several other Deputies questioned the process via parliamentary questions, and in responses to Deputy Gary Gannon⁷⁸ and Deputy Sean Crowe⁷⁹, for example, Minister of State Josepha Madigan said:

“The Department of Education and the NCSE have put in place a suite of supports to assist schools in completing the educational component of the HSE’s AON process. These include:

- Detailed guidance,
- Short video for use by schools setting how to comply with the process;
- Email support,

⁷⁶ The full information note and related materials are available here gov.ie - [Report of Education Needs for the purpose of Assessment of Need \(Disability Act 2005\) \(www.gov.ie\)](http://gov.ie) .

⁷⁷ [Saincheisteanna Tráthúla - Topical Issue Debate – Dáil Éireann \(33rd Dáil\) – Tuesday, 25 Oct 2022 – Houses of the Oireachtas](#)

⁷⁸ [Special Educational Needs – Tuesday, 8 Nov 2022 – Parliamentary Questions \(33rd Dáil\) – Houses of the Oireachtas](#)

⁷⁹ [Special Educational Needs – Thursday, 27 Oct 2022 – Parliamentary Questions \(33rd Dáil\) – Houses of the Oireachtas](#)

- Dedicated support line – this line is staffed by education professionals who will assist schools in completing the process.”

Following warnings from principals, teachers’ unions, disability groups and campaigners, the national roll-out of the new arrangements contained in the information note was paused. This was welcomed by John Boyle, the General Secretary of the Irish National Teachers’ Organisation, who said that the proposed new process involved “passing the buck” to school staff⁸⁰. Sixty-six schools, however, are to continue with the new system, which is currently being referred to as a trial⁸¹. School principal and podcaster Simon Lewis described the ordeal as “the NCSE directing schools to do the job a High Court decision had placed on them”. He called for the NCSE to be decommissioned⁸².

While the Committee recognises the important role schools have to play supporting students, careful consideration should be given to those processes and responsibilities must be matched with resources. As mentioned, the Committee sent a survey to colleagues in the European Center for Parliamentary Research and Documentation network (ECPRD⁸³) to enquire about these issues in other jurisdictions. As many of the responses were education-focused it is worth considering some of the information received.

Generally, where respondents reported that schools are heavily involved in the AON process and special education provision, resources tended to be in place to match those specific responsibilities.

Several jurisdictions reported having a Child Welfare Commission or similar within each school or having multidisciplinary educational support teams in place in each school.

A number of jurisdictions reported that a network of mobile special educational professionals travel to schools to provide the required extra resources as needed.

⁸⁰ [National rollout of ‘unlawful’ school assessments halted – The Irish Times](#)

⁸¹ [Update on the Assessment of Need – National Council for Special Education – Working to deliver a better special education service \(ncse.ie\)](#)

⁸² [Anseo.net - If I were the Minister for Education on Apple Podcasts](#)

⁸³ [ECPRD | European Center for Parliamentary Research and Documentation \(europa.eu\)](#)

These generally were comprised of special education teachers and mobile assessors/conductors.

Many jurisdictions reported that there are local bodies covering a certain geographically area with responsibility for assessing special educational needs. The names given to these local units included 'psychological and pedagogical counseling centres', 'education commissions', 'regional centres', 'regional school supervisory authorities', regional 'committees' and 'educational and counseling support centres'.

These regional bodies with responsibility for assessing special educational needs were generally staffed with multidisciplinary teams comprised of some mix of the following: doctors, psychologists, teachers and specialists for children with disabilities, resource teachers, special pedagogues, speech therapists and other specialists if necessary, or representatives of the regional departments of education.

The Committee recommends that:

25. An education campaign should be launched to provide parents, care-givers and children with accessible information about the AON process.

26. Appropriate tools, guidance and supports should be provided for assessment officers and all those working in disability services generally.

27. Input from disabled people, families, carers and therapists should be central to the design of the interim guidance and of any new SOP, in addition to the work of the National Clinical Programme for People with Disabilities generally.

28. Where schools are involved in the AON process, they must be properly resourced, either through in-house multidisciplinary teams, regional special education centres or mobile special education support and assessment teams.

29. Communication with schools about their role in the AON process, once clarified, needs to be improved and buy-in and collaboration with them established.

30. The Progressing Disability Services audit should assess how the National Clinical Programme for People with Disabilities is working, including analysing how many

people with lived experience of having a disability are involved, whether that amount is enough, and whether they are being enabled to provide meaningful input into the relevant fora and policies.

31. Assessments should be followed up with appropriate signposting of services to support those who need them throughout their life.

32. The Department should reimburse parents and caregivers, on a case-by-case basis, in respect of private medical fees incurred in securing alternative services, in circumstances where there are delays in receiving an assessment for their child through the public system.

5. Standards, Acts and Conventions

A number of international conventions, professional standards and pieces of legislation are relevant to the provision of AONs and other disability services to children. The role these could play in strengthening children's rights and informing policy is well-explored in the Ombudsman's report and in the submission received from his office, and informs many of the following recommendations.

Acts

As outlined in the introduction, there are two main Acts at play in the delivery of key services to children: the Disability Act, 2005 and the Education for Persons with Special Educational Needs (EPSEN) Act, 2004. At the time of writing this report, a review of the EPSEN Act was ongoing, and as discussed, many stakeholders called for a review of the Disability Act. Stakeholders discussed Section 13 of the EPSEN Act as an important part for review and commencement, as that is the section where the Oireachtas agrees to provide the resources necessary to deliver the Act.

The Committee is supportive of a review of the Disability Act but is cognisant of fears that a review may lead to a dilution of the rights it contains, and that a careful balance will need to be struck to ensure it is rights and needs based, and not overly diagnosis-

led. As such, the Committee recommends a review of the Disability Act, but under specific conditions, outlined in the recommendations section below.

Conventions

While Ireland is a signatory of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) , it has not ratified the associated [Optional Protocol](#), which would allow people to raise complaints about violations of their rights with the UN more effectively. Ireland has signed up to the United Nations Convention on the Rights of the Child (UNCRC) and the Optional Protocol to that convention. It has not, however, incorporated the UNCRC into national legislation, which would be a progressive way increase protections for children. Other jurisdictions have done so, with Sweden being a recent example.

The Committee recommends the ratification of the UNCRPD Optional Protocol without any further delay. Furthermore, the UNCRC should be incorporated into domestic legislation.

Standards

In the judgment of 11 March 2022, against the SOP, the High Court expressed concern about a state of confusion evident as to the status of the HIQA Standards⁸⁴ . The Ombudsman informed the Committee that new standards relating to AON are required, but not being developed due to resources and capacity within HIQA being diverted elsewhere. HIQA must be resourced to provide appropriate and up-to-date standards for AON. These should be developed as a priority.

Therapists who engaged with the Committee also raised concerns about the SOP, stating that it is currently neither evidence-based nor good practice, putting them in a position where they are potentially being told to operate in a way that is contrary to the standards prescribed by CORU, Ireland's health profession regulator. The HSE must work with therapists collaboratively to ensure that policies and procedures are CORU compliant.

⁸⁴ Para 179 in [pdf \(courts.ie\)](#)

The Committee recommends that:

33. A review of the Disability Act should be undertaken, but under the following specific conditions:

A. The Disability Act and ESPEN Act must be reviewed in tandem. The fact that different Government departments have responsibility for these pieces of legislation should not be a barrier to the 2005 Act being considered in the context of the review of the 2004 Act, and, if necessary, changes being made to both at that stage.

B. Any review of the Disability Act should not remove or dilute any rights contained therein, including the right to a comprehensive, complete assessment of need.

C. The legislation must be child centred, rights-based, be UNCRPD compliant and be underpinned by a needs-led rather than a diagnosis-led model.

D. The review should be undertaken by an independent expert group, to include representatives of Disabled Persons Organisations (DPOs) and their advocates.

E. As with all initiatives aimed at improving disability services, the review of the Act and implementation of changes arising from it must take a coordinated, whole of Government approach.

F. The review of the Act should not impact service provision in the meantime. Shortcomings within the Act are not an acceptable justification for the failure to provide assessments and interventions to all children who need them in a timely manner.

G. Any review of the Disability Act must preserve the element that refers to provision “without regard to cost or capacity” and should impose a right to interventions as well as assessments within statutory timeframes and without regard to cost.

34. The review of the Disability Act 2005 should consider:

A. 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.

B. The amendment of section 2 to a definition of disability which is rights-based, child-centred and inclusive.

C. The amendment of section 7 to ensure a best interest, holistic, multidisciplinary, needs-based approach to AON.

D. 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.

35. The UNCPRD Optional Protocol should be ratified without any further delay.

36. The UNCRC should be incorporated into domestic law as a matter of priority.

37. HIQA must be resourced to provide appropriate and up-to-date standards for AON. These should be developed as a priority.

38. The HSE must work with therapists collaboratively to ensure that policies and procedures are CORU compliant.

39. There should be an immediate cessation of the SOP.

APPENDIX 1 – INTERNATIONAL INSIGHTS

The European Center for Parliamentary Research and Documentation is a network which enables information exchange⁸⁵. The ECPRD's members are Parliaments where the President is a member of the European Conference of Presidents of Parliament⁸⁶.

The Committee conducted a survey, via the network, to get some international insights into the organisation of AONs and disability services for children in other jurisdictions. It was sent to the network for responses in April 2021. Respondents were also asked about processes and problems or challenges in their jurisdictions. A total of 30 replies were received. Many jurisdictions did not report any problems with their systems for providing assessments of need. Several even explicitly said that the systems work well. The questions asked and a summary of the results of the survey is available [here](#).

Lawmakers should give consideration to working collaboratively with their international counterparts to share learnings and solutions.

APPENDIX 2 – TRANSCRIPTS AND SUBMISSIONS

Transcripts

[1 December 2020](#)

[8 December 2020](#)

[15 December 2020](#)

[2 March 2021](#)

[11 May 2021](#)

[22 March 2022](#)

[2 June 2022](#)

⁸⁵ [ECPRD | European Center for Parliamentary Research and Documentation \(europa.eu\)](#)

⁸⁶ The list of parliamentary chambers which are member can be viewed here [ECPRD | European Center for Parliamentary Research and Documentation \(europa.eu\)](#)

Submissions

The following are some submissions which were made to the Committee during its consideration of these issues:

[Ombudsman for Children](#)

[Psychological Society of Ireland](#)

[Emma Butler and Rita Treacy](#)

[Involve Autism](#)

In addition to the submissions listed, the Committee received a significant amount of correspondence and additional briefing documents on this topic over the last number of years, from many stakeholders, including concerned parents and professionals working in the sector. The Committee is extremely grateful for the first-hand experience and insights relayed through the material it receives, which helps to inform reports such as this one.

APPENDIX 3 – TERMS OF REFERENCE FOR COMMITTEES

This report is produced by the Joint Committee Children, Equality, Disability, Integration and Youth under its Terms of Reference ([available here](#)) as agreed by Dáil and Seanad Éireann. Any Conclusions or Recommendations arrived at have been agreed by the Committee. They do not represent the views of either House of the Oireachtas unless these have formally endorsed the report. It is important to note that the report is the agreed collective view of members of the Committee. However, individual members may not agree with all Conclusions or Recommendations arrived at.

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