AN COMHCHOISTE UM SLÁINTE

An Tuarascáil ar an Nós Imeachta Oibríochta Caighdeánach Nua chun Measúnú a dhéanamh ar Riachtanas faoin Acht um Míchumas, 2005

Eanáir 2019

JOINT COMMITTEE ON HEALTH

Report on the New Standard Operating Procedure for Assessment of Need under the Disability Act 2005

January 2019
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The Disability Act 2005 sets out to support the participation of people with disabilities in our society. The Act also intends to deliver improved access to public services to people with disabilities.

Part 2 of the Act outlines the main provisions of the Assessment of Need (AON) process. The AON process provides for a child, who has a disability, with an assessment of their needs as a result of their disability and a statement of the services they require.

The Act also stipulates that the assessment should be undertaken without regard to cost or the capacity to provide any services identified in the assessment.

The Health Service Executive has proposed a new Standard Operating Procedure which it believes will better meet the stipulations of the Act. It also proposes to standardise the Assessment of Need process.

Therapist representatives and parent advocacy groups have raised a number of concerns regarding the SOP. In response to these concerns, the Committee held two meetings, on the 27 June and 17 October 2018, to examine the proposed Standard Operating Procedure. The Committee met with representatives of the HSE and a wide variety of stakeholders including representatives of the Association of Occupational Therapists in Ireland (AOTI), the Psychologist’s Society of Ireland (PSI), the Dedicated Children’s Advocacy Warriors (DCA Warriors) and the Irish Association of Speech and Language Therapists (IASLT).

It is important to note that the SOP is still under development and that talks between the HSE and Fórsa are ongoing. The Committee acknowledges the potential benefits of the standardisation of the AON process. However, the Committee also recognises the need to improve the availability of and access to additional services from the point of view of children and their parents. Early diagnosis, early action and early treatment are key to positive outcomes. Any new process must endeavour to provide these key objectives and place the child’s wellbeing central to the outcome.

The Committee is concerned at the lack of consultation between the HSE and therapists and the lack of information provided to parents regarding the SOP.
The Committee is hopeful that effective consultation between the parties can establish an AON process that is both consistent and able to provide additional services in a timely manner.

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. At both of its meetings, 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.

The Committee expresses its gratitude to all stakeholders who attended the meetings and contributed to a thorough debate. This is an important topic and one which impacts on many individuals and families in Ireland. The Committee recommends that the Health Service Executive and the Department of Health should reflect on the testimony of the witnesses who attended the meeting and respond accordingly. The Committee has made a number of recommendations echoing the issues discussed. Many of the recommendations call for additional resources and the Committee is aware that such resources are finite. However, rather than considering the immediate cost of such resources, they should be considered as an investment from which there are many potentially positive health outcomes and cost-benefits in the short-term.

Dr. Michael Harty, T.D.
Chair
Joint Committee on Health
23 January 2019
# Acronyms and Abbreviations

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tr>
<td>AO</td>
<td>Assessment Officer</td>
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<td>AON</td>
<td>Assessment of Need</td>
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<tr>
<td>AOTI</td>
<td>Association of Occupational Therapists of Ireland</td>
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<td>CHO</td>
<td>Community Health Organisation</td>
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<td>DCA Warriors</td>
<td>Dedication Children’s Advocacy Warriors</td>
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<td>EIT</td>
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<td>Irish Association of Speech and Language Therapists</td>
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<td>SOP</td>
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Executive Summary

The Disability Act 2005 defines an Assessment of Need as a process which, in respect of a person with a disability, “determines the health and education needs (if any) occasioned by the disability and the health services and educational services required (if any) to meet those needs”.

Part 2 of the Act outlines a number of stipulations in terms of the Assessment of Need. The Health Service Executive (HSE) has noted that there are a variety of interpretations of the wording of the Act and, as a result, there is an inconsistent approach to the process among Community Health Organisations (CHO). In response to this, the HSE is proposing a new Standard Operating Procedure (SOP) for Assessment of Need (AON).

The Joint Committee of Health held two meetings, on 27 June and 17 October 2018, to discuss the new Standard Operating Procedure on Assessment of Need. The meetings were attended by representatives of the Health Service Executive who gave details of the new Standard Operating Procedure. The meetings were also attended by representatives of the Association of Occupational Therapists of Ireland (AOTI), the Psychological Society of Ireland (PSI), the Dedicated Children’s Advocacy (DCA) Warriors and the Irish Association of Speech and Language Therapists (IASLT) who outlined their concerns in relation to the new SOP.

The report examines three main areas. Firstly, it details the Assessment of Need process and draws attention to the concerns of stakeholders regarding the changes proposed in the new SOP. With regard to the AON, the Committee recommends further consideration of the process, specifically in relation to the initial Standard Additional Information Form and the Preliminary Team Assessment. The Committee recommends that such consideration include continuous consultation with front-line therapists and parents. The Committee is adamant that the new process must prioritise the child and provide for early access to intervention services.

Secondly, the report examines communication between the HSE and other stakeholders. The Committee believes that front-line therapists and parents provide invaluable insight and personal experience that is currently being overlooked in drafting the SOP. Simultaneously, a number of issues have festered that are potentially soluble but are ongoing due to a lack of communication between therapists, parents and the HSE. The Committee believes that the
assessment of need process would be best served through a consensus between stakeholders and recommends the establishment of a continuous consultation process between all stakeholders. The Committee also recommends the participation of parent representation during the drafting process.

Thirdly, the report examines early intervention and assesses a number of obstacles which are preventing the effective implementation of this strategy. Obstacles include long waiting lists for assessment and accessing services, the structure of disability teams and resource shortages including a shortfall in therapists. The importance and benefits of early intervention are many and such obstacles are deeply harmful to those requiring services.

The Committee makes a number of recommendations relating to these obstacles. The Committee is alarmed at the long waiting lists throughout the country and notes the staff shortages within disability teams throughout the CHOs. The Committee believes that this issue should be a priority for the HSE and recommends that appropriate resources should be allocated to ensure that these teams can operate effectively. This report also recommends an evaluation of the recruitment process to ensure a swifter and more efficient operation.

The Committee supports the Progressing Disability Services for Children and Young People and recommends that it should be reconfigured without delay to ensure a better service for those with disabilities.

Finally, the Committee wishes to emphasise the value of early intervention in child health services. The Committee is cognisant of the difficulties in resourcing such services, but believes that it is essential that resources are made available to children with disabilities as early as possible. Failure to adequately provide services to children at an early developmental stage will result in increased costs for the provision of educational services, potential negative societal effects and missed opportunities for individuals. As a result, it is imperative that support is provided at the earliest possible stage.
Summary of Recommendations

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

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

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

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

5. The Committee recommends that the HSE give further consideration to the testimony of stakeholders and their concerns regarding the Preliminary Team Assessment. The Committee has concerns that the proposed Assessment does not prioritise the child’s best interests and may further delay access to services. The Committee recommends further consultation between the HSE, parent advocate groups and the therapists.
6. The Committee recommends continuous discussions between the HSE, parents and front-line therapists with regard to the Assessment of Need process. The Committee especially believes the experience and insight of therapists and parents is valuable and should be utilised in the drafting of the AON process. The Committee believes that a consistent approach to the AON process is vital but recommends that the outcome of the process must be the provision of early diagnosis, early intervention and early treatment.

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

8. The Committee has grave concerns regarding the current waiting lists on the Assessment of Need process. The Committee is of the view that in order to address these waiting lists, the following must be achieved without delay:
   (i) reconfiguration of CHOs,
   (ii) recruitment of additional therapists for Disability Teams
   (iii) provision of adequate resources to Disability Teams.

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

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

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

1.1 Disability Act 2005

The Disability Act 2005 sets out to advance and underpin the participation of people with disabilities in society by supporting the provision of disability services and improving access to mainstream public services.

The Act defines a disability as a "substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment."

1.2 Part 2 of the Act – Main Provisions

Part 2 of the Disability Act was implemented in June 2007. It sets out provisions for assessment of needs, service statements and redress.

The Act maintains that children who have or may have a disability are entitled to:

i. an assessment of their health needs arising from the disability,
ii. an assessment report,
iii. a statement of the services they will receive,
iv. make a complaint if they are not happy with any part of the process.

The Act also specifies that:

- An assessment officer (AO) must carry out assessments of applicants or arrange for an assessment to be carried out by another assessment officer or another person with appropriate experience;\(^2\)
- When an AO is of the opinion that there is a need for an education service to be provided for an applicant, the AO will write to the National Council of Special Education requesting that an appropriate person carry out an assessment;\(^3\)
- The Act stipulates that assessments are to be undertaken without regard to cost or the capacity to provide any services identified in the assessment;\(^4\)

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\(^2\) Section 8 (2)

\(^3\) Section 8 (3)
1.3 Requirement for Change

In 2017, a HSE review of Part 2 of the Act, highlighted an inconsistent approach to the AON process among Community Health Organisations (CHO) across the country.

At the Committee meeting on 27 June 2018, representatives of the HSE informed the Committee that:

“the Act includes several definitions that are open to interpretation operationally and that this has led to an inconsistent approach as well as inequity in terms of time afforded to ‘assessment’ versus ‘support or treatment’ interventions with children and their families”.

In order to address the inconsistency, the HSE issued a number of “Guidance Notes” to assessment officers clarifying aspects for the AON process; however there has been no nationally standardised or agreed definition of AON.

In addition, an increase in the number of applications for an AON assessment (see figure 1), has created further pressure on disability teams.

The HSE is now proposing a new Standard Operating Procedure for Assessment of Need with the objective of:

i. addressing the inconsistencies in approach among CHOs;
ii. addressing the provisions of the Act;
iii. tackling the increasing number of applications for AON.

![AON applications chart](image)

*Figure 1: Number of AON applications 2008 & 2017: Source HSE*

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Section 8 (5)
2. Early Intervention

Early intervention is defined as a coordinated, multidisciplinary service that is provided to young children at risk of developmental delays, with the intention of occasioning positive effects on their development. In support of early intervention, the UN Convention on the Rights of Persons with Disabilities declared that:

“States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.”

It also stated that:

“In particular, States Parties shall:

- provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- provide these health services as close as possible to people’s own communities, including in rural areas;

Early intervention is reported to result in lasting positive outcomes and prevents difficulties from becoming entrenched in later childhood and adulthood.

With regard to the AON process, early intervention comprises of identifying the needs of children with disabilities at a pre-school age and allowing access to services such as speech and language services. Identifying additional needs may be problematic as some traits may be difficult to detect at an early age. Therefore, continuous monitoring by a multidisciplinary team is required to identify any additional needs.

Representatives of the AOTI stated that there was “a golden window of opportunity in the children’s lives that is being missed”. Such a window is transient and failing to provide early intervention will often induce a number of detrimental effects:

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5 Article 25
6 Article 25 (b)
7 Article 25(c)
• **Effects on Children**
  Early intervention is most effective from the ages of 0-6 years of age. However, the brain development of children is at its most intense between the ages of 0 to 3 years and therefore early additional services are at their most effective during this period. A failure to provide services at this stage will often result in a deteriorating effect on the child.

• **Monetary Effects on Family**
  Due to the difficulty in accessing additional services, many families attend private support services. The Committee heard evidence regarding difficulties that families have financing such services. There may also be indirect costings to families such as loss of income when caring for a child with additional needs.

• **Monetary Effects on Health Budget**
  In 2010, the Scottish Finance Committee completed a comprehensive inquiry into preventative spending. The report details a correlation between investment into early intervention and the beneficial rate of return, and was supportive of the positive impact of preventive spending in a range of services, including healthcare.

The Assessment of Need aspires to provide early intervention. However, numerous barriers diminish the benefits of early intervention services. The Committee is aware that are many financial pressures on a variety of health services and further requests for investment is demanding. However, the Committee notes the social and cost-benefits of early investment and supports the investment into early intervention.

### Recommendations

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

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

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9 Melhuish P. E., 2010
10 http://archive.scottish.parliament.uk/s3/committees/finance/reports-11/fir11-01.htm#1
3. The Assessment of Need Process

The Disability Act outlines a number of statutory timelines in which specific outcomes must be completed.

The current Assessment of Need process (see figure 2) has 3 stages;

i. Initial Screening – the assessment officer (AO) decides on the assessment needs of the child. This must be completed within three months from the time the application is received.

ii. Assessment – The child receives further assessment by a variety of therapists. This stage must also be completed within months.

iii. Service Statement – the AO completes a service statement and completes the AON report. This must be completed within one month.

The new Standard Operating Procedure (see figure 3) proposes a number of changes to the AON process.

i. Initial Screening – The AO decides whether or not the child has a disability. This stage must be completed within three months.

ii. Assessment – The child receives a Preliminary Team Assessment. The new SOP proposes that two clinicians will complete a 90 minute assessment. Based on this assessment, the AO will then complete an AON report. This stage must be completed within three months.

iii. Service Statement – The AO will send a service statement to the Liaison Officer. This stage must be completed within one month.
Figure 2: Current Assessment of Need Process

Current Process: Application for AON received

Stage One
Act allows 3 months

Is the child eligible based on his/her age?

NO

Application refused

YES

AO meets family, completes additional information form, gathers reports
AO decides on assessment needed

Stage Two
Act allows 3 months

AO arranges referral to one or more services for clinical assessment

Assessment 1

Summary report prepared and returned to AO

Assessment 2

Summary report prepared and returned to AO

Assessment 3

Summary report prepared and returned to AO

AO compiles AON report
AON report sent to Liaison Officer

Stage 2
Act allows 1 month

Liaison Officer completes Service Statement
Service Statement/AON report issued
Figure 3 - Proposed Standard Operating Procedure for Assessment of Need Process

**Stage One**

- Application for AON received
- **Is the child eligible based on his/her age?**

**NO**
- Application refused

**YES**
- AO speaks with family, arranges for completion of additional information form, gathers reports
- **Does the child need a disability service?** (based on access policy criteria)

**Stage Two**

- **Stage One Act allows 3 mths**
- Referral is arranged to appropriate services outside of AON process
- **NO**
- **YES**

- AO arranges referral to the Children’s Network Disability Service for clinical assessment

- **Stage Two Act allows 3 mths**
- Child is seen for Preliminary Team Assessment within statutory timelines
- **Child receives initial intervention or waitlisted for further assessment**

- **Summary report prepared and returned to AO**

- **Stage Two Act allows 3 mths**
- AO compiles AON report
- AON report sent to Liaison Officer

- **Stage Two Act allows 3 mths**
- Liaison Officer completes Service Statement

- **Additional services/assessments identified as part of Service Statement**
- Service Statement/AON report issued

**Stage One Act allows 3 mths**

**Stage Two Act allows 3 mths**

**Stage Three Act allows 1 mth**
3.1 Stage 1 – Initial Screening

3.1.1 Background

Stage 1 of the Assessment of Need process begins following receipt of an application by the assessment officer (AO) from the family of the child. The Act compels the AO to complete stage 1 within three months from the date of receipt of the application\(^\text{11}\).

Under stage 1 of the current AON process the assessment officer initially determines whether or not the child meets the age criteria for the process. Once confirmed, the AO will meet with the family and child. The AO will conduct an examination of all relevant reports that relate to the child’s needs. The AO will then determine the assessment needs of the child and initiate further assessments by other therapists (stage 2).

3.1.2 Changes under New SOP

Under the new Standard Operating Procedure, the family of the child will be required to submit a standard additional information form, which is tailored to tie up with the national access policy and adapted according to the child’s age. The pre-existing form is general for all age groups. The HSE informed the Committee that the new form is intended to provide more detailed information which will allow an AO determine the assessment needs of a child. The AO may also telephone the family to seek further information.

The AO will then determine whether or not the child has a disability. If the child is not considered to have a disability, he or she will be referred to the appropriate service outside of the AON process.

If a child is deemed to have a disability, the child will be referred to the Children’s Network Disability Service for Clinical Assessment (Stage 2).

\(^{11}\) Disability Act 2005, 9(5)
3.1.3 Key Issues

(i) Standard Additional Information Form

Representatives of AOTI and PSI expressed concerns that the standard additional application form does not provide a substantial assessment of a child and therefore, cannot adequately inform an assessment officer on whether or not a child has a disability. Representatives also explained that the Assessment of Need requires careful observation by clinicians to uncover nuances in a child’s behaviour which indicate that the child requires additional services. Consequently, an initial determination on whether or not a child has a disability could not be achieved through this process.

Representatives were also critical of the complexity of the form, which may lead to a misdiagnosis of a child’s needs. For example, parents may not be aware of specific behaviours that may indicate further complexity to a child’s needs and, consequently, there may be a risk that such behaviours will not feature on the form. Representatives of AOTI also noted that parents and children are often anxious at initial meetings, which is likely to impact on the child’s presentation and, potentially, the outcome of the assessment.

Furthermore, additional information may also be requested from the parents in a telephone conversation. Similarly, this medium may be less that satisfactory in communicating information regarding the child’s behavioural traits.

Representatives of HSE stated that the additional information sought from parents was valuable and that this approach “is not in order to undermine or disrespect the value of clinical reports, but rather to highlight the important role that parents play in respect of their children’s growth and developmental potential”.

Representatives also explained that an initial assessment should result in a therapist giving some guidance and pathways for a child. However, due to the large waiting lists, accessing service may be delayed for several years. The initial assessment does not adequately provide pathways and advice to parents.
(ii) **Statutory Time**
The Act states that stage 1 must be completed within three months of receipt of the application. However, a number of CHO’s have excessive delays in completing stage 1.

Following stage 1 of the new SOP a child attempting to access services may be deemed not to have a disability and moved to a waiting list to access services outside of the AON.

Alternatively, a child may be deemed to have a disability and referred to therapists for further assessment through the Preliminary Team Assessment in stage 2. Within either of these scenarios, the child may still await appropriate assessment or effective intervention for some time.

Section 6 of this report examines waiting times in further detail.

### Recommendations

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

4. The Committee recommends that the new Standard Operating Procedure is not brought into use before consultation with front-line therapists and parents. Such a consultation process should involve discussions regarding specific concerns of stakeholders as well as informing all parties of the requirements and specification for the new SOP. The Committee welcomes the HSE’s commitment to engage with assessment officers and instruct that the current AON process should be in use. However, the Committee is concerned that, at present, communication between the HSE and assessment officers is not effective.
3.2 Stage 2 – The Assessment

3.2.1 Background

Stage 2 commences when an assessment officer, having decided on the assessment needs of a child, refers them to one or more services for further clinical assessment. The stage is concluded when the AO delivers an Assessment of Need report to the Liaison Officer. The Act requires that this process is completed within three months.

Under the current AON process, the AO will refer the child to one or more services for clinical assessment. The child will then undergo a multidisciplinary assessment which will involve interaction with a number of therapists. Each therapist will complete an assessment and report back to the assessment officer. The AO will then complete the AON report summarising the findings of the multi-disciplinary assessments. The AON report will be referred to the Liaison Officer.

3.2.2 Changes under New SOP

Under the new SOP, an assessment officer will refer a child to the Children’s Network Disability Service for a preliminary team assessment.

Following this assessment, a summary report will be prepared by the Disability Service and returned to the assessment officer, who will then prepare an Assessment of Need report. This will then be sent to the Liaison Officer.
3.2.3 Key issues

(i) Preliminary Team Assessment

The objective of the Preliminary Team Assessment is to provide a report to the assessment officer which will recommend initial interventions required. However, once these recommendations are made, the child is often waiting for access to the service for a considerable time. Stakeholders were particularly critical of several aspects of the Preliminary Team Assessment.

One of the main concerns regarding the Preliminary Team Assessment is that it will be the first point of contact for all children. Representatives of AOTI mentioned that for some children, it would be more suitable to undergo a full team assessment. The representatives also told the Committee that the intention of the Act was to have an AON completed within 6 months, but under the new SOP, only a preliminary assessment will be completed within 6 months.

Other concerns expressed to the Committee include the following:

- Representatives told the committee that the proposed 180 minutes assessment does not afford the therapist time to assess the child across a variety of environments, such as school, home and clinic, which is considered best practice for a comprehensive assessment. The HSE explained that this aspect was still under discussion and considered the matter soluble. The Committee, however, are concerned about the discrepancy between the initially proposed time and the average time required by therapists to complete an adequate assessment.

- The proposed SOP will increase pressure on the Assessment of Need waiting lists. Previously an initial determination set out some of the assessment needs of the child and stage 2 provided further details as to the requirements. Under the new SOP, stage 2 only begins to provide a preliminary assessment which will be sent to the assessment officer. This will further delay the wait for a child to access additional services.

- 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 time-frames.

- 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. Representatives of the PSI referred to a number of occasions on which the independent disability appeals officer has found against the HSE for failing to provide a comprehensive assessment of need, including failures to address the specific concerns of the applicant in relation to the diagnostic assessment, as required by HIQA standards.

- The proposed assessment gives scope for the misdiagnosis of a child. Representatives gave details on how initial meetings with the family and children can be anxiety-inducing and as a result the clinicians may not be able to accurately assess the needs of the child in these early stages. The new SOP places constraints on clinicians regarding autonomy and decision-making. Representatives added that psychological assessment can be complex and clinicians need the freedom to conduct the necessary assessments that provide an appropriate diagnosis.

- The SOP requires that clinicians identify whether a child has a permanent disability that warrants further assessment in order to confirm a diagnosis. There are concerns that this places significant pressure on therapists to make an important decision with what may be limited information, resulting in inappropriate referrals to diagnostic services or potentially inadequate or harmful intervention strategies. Similarly, under the new SOP guidance notes for assessors, it is stated that no family should leave the clinic without some strategies to support the child. Representatives are supportive of this measure but do not believe that this is possible without a full team assessment, as opposed to the proposed preliminary team assessment.

- The procedure places a number of professionals in breach of their own code of professional conduct. Such codes include the PSI code of ethics\(^\text{12}\) and the CORU framework for a common code of professional conduct and ethics of 2010\(^\text{13}\).


• 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 Preliminary Team Assessment will negatively impact clinicians as it will pull them away from their positions in Early Intervention Teams, School Age Disability Teams and Primary Care Teams in order to carry out screening as part of the PTA.

• The proposed SOP will impact most negatively in those geographical areas where there are gaps in service and extremely long waiting periods to receive comprehensive assessments outside of the AON.

The Committee acknowledges stakeholders’ support to standardise the Assessment of Need process. However, 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 Disability Act aims to underpin the participation of people with disabilities in society by supporting the provision of disability services and improving access to mainstream public services.

The Committee recommends that people with disabilities and their parents should be central to the process. The Committee also recommends that such a process should arise from a consensus between the HSE, front-line therapists and parents. To achieve this, each party must be allowed to participate in the development of the SOP.

Such a process also requires continuous review and all parties should be allowed a say in this matter.
5. The Committee recommends that the HSE give further consideration to the testimony of stakeholders and their concerns regarding the Preliminary Team Assessment. The Committee has concerns that the proposed Assessment does not prioritise the child’s best interests and may further delay access to services. The Committee recommends further consultation between the HSE, parent advocate groups and the therapists.
3.3 Stage 3 – Service Statement

3.3.1 Background

In Stage 2, the Liaison officer, having received the Assessment of Need form from the assessment officer, will complete the Service Statement for the child. This will set out the services required for the child.

Under the new SOP the Liaison Officer will also consider the additional assessments that the child may have received. Stage 3 must be completed within one month of the Liaison Officer receiving the AON report.

3.3.2 Key Issues

The Committee heard evidence of long delays to providing additional services. The Committee has grave concerns regarding these delays and the impact upon providing early intervention. These delays are discussed further in Section 6 of this report.
4. Communication

The Assessment of Need is a complex process, integrating numerous activities and a variety of participants. For such a process to function effectively, strong and continuous communication between participants is essential. However, the Committee heard evidence of several scenarios where effective communication was absent.

Representatives of the HSE told the Committee that the SOP is still being developed. However, representatives from the DCA Warriors provided examples to the Committee where the new SOP was in use by some assessment officers. The Committee welcomed the HSE’s response to this claim and its commitment to re-issue instructions to AOs not to use the new SOP until it has been finalised. However, the Committee has concerns regarding the initial miscommunication of such information. The Committee is also concerned at the lack of information being provided to parents regarding the SOP.

Similarly, there is confusion among front-line therapists regarding the new SOP. Many of the therapist representative groups had not been involved in consultations and information regarding consultations was not adequately communicated to these groups. Representatives noted that they were often the first point of contact for families, with first-hand experience of the AON process and continuous interaction with children and families. Despite this, front-line staff were often omitted from the consultation.

The Committee also heard that many GPs and pharmacists are not aware of the AON process or indeed how they might refer children.

The Committee was addressed on the difficulties that assessment officers and therapists experience in accessing reports and other relevant information regarding a child’s assessments. This results in delays in the completion of assessments and in providing services to children.

The Committee recommends that a central database should be available which will allow AO’s and therapists access the required information instantaneously. Such a database may also provide instructions to AOs and therapists in real-time.
**Recommendations**

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

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

Community Health Organisations are a broad range of services that are provided outside of the acute hospital system. Services include Primary Care, Social Care and Mental Health. There are currently nine Community Health Organisations covering the Irish Health Service and each CHO represents a geographical region (see figure 4). The HSE is currently in the process of reconfiguring CHOs. The key objective of reconfiguration is to integrate the various elements to create a unified healthcare system. This involves the streamlining of services to have multi-disciplinary teams functioning within one location and working together.

Stakeholders from all groups support the reconfiguration of CHOs. The reconfiguration will allow families a single-point of access to disability services and should lead to a more efficient AON process. However, stakeholders were critical of the level of resources being allocated to reconfiguration.

Representatives commented that reconfiguration is more achievable in smaller CHOs as this requires the least investment. Such CHOs are still under-resourced but these areas are, in general, coping better than those yet to be configured and requiring substantial investment. At present, only two of the nine CHO’s have been reconfigured and these are in areas where multi-disciplinary teams are already co-located and working together.

Larger CHO areas are more complex to reconfigure and a lack of investment and management has highlighted many shortcomings in resources.
<table>
<thead>
<tr>
<th>Area/CHO</th>
<th>Local Health Offices</th>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Donegal, Sligo/ Leitrim/ West Cavan and Cavan / Monaghan</td>
<td>389,048</td>
</tr>
<tr>
<td>2</td>
<td>Galway, Roscommon and Mayo</td>
<td>445,356</td>
</tr>
<tr>
<td>3</td>
<td>Clare, Limerick and North Tipperary/ East Limerick</td>
<td>379,327</td>
</tr>
<tr>
<td>4</td>
<td>Kerry, North Cork, North Lee, South Lee and West Cork</td>
<td>664,533</td>
</tr>
<tr>
<td>5</td>
<td>South Tipperary, Carlow/ Kilkenny, Waterford and Wexford</td>
<td>497,578</td>
</tr>
<tr>
<td>6</td>
<td>Wicklow, Dun Laoighaire and Dublin South East</td>
<td>364,464</td>
</tr>
<tr>
<td>7</td>
<td>Kildare/ West Wicklow, Dublin West, Dublin South City and Dublin South West</td>
<td>674,071</td>
</tr>
<tr>
<td>8</td>
<td>Laois/ Offaly, Longford/ Westmeath, Louth and Meath</td>
<td>592,388</td>
</tr>
<tr>
<td>9</td>
<td>Dublin North, Dublin North Central and Dublin North West</td>
<td>581,486</td>
</tr>
</tbody>
</table>

Figure 4: Community Health Areas by Geographic Area and Population
6. Waiting Lists

The failure to reconfigure many of the CHO\textsubscript{s} is evident in the numerous waiting lists in the Assessment of Need process.

There are considerable inconsistencies in the waiting lists between CHO\textsubscript{s}, which stakeholders indicated is reflective of the amount of investment and reconfiguration in each CHO.

For example, the Committee heard that CHO 4 (Kerry, North Cork, North Lee, South Lee and West Cork.) is one such area that is experiencing major difficulties. This area receives the highest number of assessment applications and completes the highest number of reports (figure 5). However, CHO 4 possesses the highest number of overdue assessments (figure 6). The Committee heard evidence that the bulk of overdue assessments are in the Cork North Lee and Cork South Lee areas which, in June 2018, accounted for approximately 86% of the overdue assessment reports in CHO4 and 37.2% of the total overdue assessment reports in Ireland (figure 7).

**Figure 5 - Total Assessment of Need Reports Completed - source HSE**
Figure 6 - Overdue Assessments, Source HS

Figure 7: Overdue Assessment for CHO 4 at end of April 2018: Source HSE
Representatives of the IASLT told the Committee that even after the delay in assessing a child, there were often further waiting times of several years to access additional services. They also noted that families are not given sufficient information on the intervention pathways needed.

The effect of these waiting times is detrimental children’s development. In addition, families were often turning to private services, creating further burden and anxiety.

The Committee notes that there are several factors contributing to these delays. Such factors include the reconfiguration of the CHO’s, additional staffing and additional resourcing of Disability Teams. Each of these factors must be prioritised by the HSE and Government to effectively address such delays.

**Recommendations**

8. The Committee has grave concerns regarding the current waiting lists on the Assessment of Need process. The Committee is of the view that in order to address these waiting lists, the following must be achieved without delay:

(i) reconfiguration of CHOs,
(ii) employment of therapist for Disability Teams,
(iii) provision of adequate resources to Disability Teams.
7. Resources

7.1 Staffing

Representatives informed the Committee that a shortage of therapists was creating further challenges for CHOs and that these shortages correlated with assessment of need waiting lists.

For example, figure 8 below details the average time (in months) that each CHO takes to complete an AON report. CHO 4 has specific difficulties. Despite CHO 4 completing the most reports (figure 5), staff shortages and high a volume of applications have resulted in an increase in the time taken to complete reports. CHO 4 is also awaiting reconfiguration. The HSE has reported that this is due to be completed in Q2 of 2019.

![Average Time (months) to Complete AON report in Q2 2018](image)

However, representatives from AOTI noted that even within CHO reconfigured services under-staffing and under-resourcing issues continued to arise.

The National Disability Network has previously estimated a shortfall of approximately 300 to 400 therapy posts throughout the health service\(^\text{14}\). Representatives of the IASLT noted an

urgent requirement for detailed workforce planning which would ascertain where gaps exist in terms of service delivery. The representatives referenced the Bacon Report of 2001\textsuperscript{15} which provided comprehensive data on therapist staffing levels and stated that a similar up-to-date report would also be beneficial. This would allow effective project management and future planning for the AON process.

Representatives of the HSE informed the Committee that €14m was allocated for 275 additional posts to progress disability services between 2014 and 2016.

However, when staff in children’s disability services were mapped in 2016 there were only 175 whole time equivalents than in 2013.

### 7.2 Time taken to Replace Staff

It is questionable whether there is a sufficient number of therapists available to fill available positions. Representatives from the AOTI noted that a panel was available to fill such positions. However, representatives of the HSE explained that many of these individuals on panels were already in other positions and moving them would create vacancies elsewhere.

Representatives of the IASLT told the Committee that another key challenges was the length of time it takes to fill vacancies and added that it can take six to eight months from one staff member walking out the door to a replacement SLT arriving. In addition, it will take some time for the new staff member to upskill in the clinical area. One of the issues is that a team cannot begin a process of replacing staff until that vacancy arises.

The Committee recommends that the recruitment process should be reviewed to examine this issue. One solution would be consideration of a process which would allow teams to highlight potential vacancies. This would allow a swifter process for replacing staff.

7.3 Additional Resources

The Committee noted that in, addition to a shortage in therapist recruitment, further resources are required to support clinicians. This will include additional administrative staff, physical infrastructure and technological resources (IT systems).

Recommendations

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

10. The Committee recommends that appropriate resources are allocated to employ the necessary number of therapists to manage the increasing number of applications for Assessment of Need in a timely manner.

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

Appendix 1: Membership of the Joint Committee on Health

Deputies:

- Stephen Donnelly (Fianna Fáil)
- Bernard Durkan (Fine Gael)
- Dr Michael Harty [Chairman] (Rural Independent Technical Group)
- Alan Kelly (Labour)
- Kate O’Connell (Fine Gael)
- Margaret Murphy O'Mahony (Fianna Fáil)
- Louise O'Reilly (Sinn Féin)

Senators:

- Colm Burke (Fine Gael)
- John Dolan (Civil Engagement Technical Group)
- Rónán Mullen (Independent)
- Dr Keith Swanick (Fianna Fáil)
Appendix 2: Stakeholders and Transcripts

The Joint Committee on Health held two meetings on 27 June 2018 and 17 October 2018 to engage with relevant stakeholders to discuss the new Standard Operating Procedure for Assessment of Need under the Disability Act 2005. The table below identifies all stakeholders who made presentations to the Committee.

27 June 2018

**Session A**
- Mr. Odhrán Allen, Association of Occupational Therapists of Ireland
- Ms. Aoife O’Malley, Association of Occupational Therapists of Ireland
- Ms. Margaret Lennon, Dedicated Children's Advocacy Warriors
- Ms. Ruth Gilhool, Dedicated Children's Advocacy Warriors
- Dr. Catherine Long, The Psychological Society of Ireland
- Mr. Michael Stoker, The Psychological Society of Ireland

**Session B**
- Dr. Cathal Morgan, Health Service Executive
- Ms. Angela O’ Neill, Health Service Executive

17 October 2018

- Ms Vickie Kirkpatrick, Irish Association of Speech & Language Therapists
- Ms Deirdre Kenny, Irish Association of Speech & Language Therapists

The transcript of the meetings of 27 June and 17 October 2018 is available online.\(^\text{16}\)

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Appendix 3: Terms of Reference of Committee

A) Functions of the Committee [derived from Standing Orders – DSO 84A and SSO 70A]

(1) The Committee shall consider and report to the relevant House(s) on-

(a) such aspects of the expenditure, administration and policy of a Government Department or Departments and associated public bodies as the Committee may select, and

(b) European Union matters within the remit of the relevant Department or Departments.

(2) The Select Committee appointed by Dáil Éireann is joined with a Select Committee appointed by Seanad Éireann (to form a Joint Committee) for the purposes of the functions set out in this Standing Order, other than at paragraph (3), and to report thereon to both Houses of the Oireachtas.

(3) Without prejudice to the generality of paragraph (1), the Select Committee shall consider, in respect of the relevant Department or Departments, such—

(a) Bills,

(b) proposals contained in any motion, including any motion within the meaning of DSO 187,

(c) Estimates for Public Services, and

(d) other matters

as shall be referred to the Select Committee by the Dáil, and

(e) Annual Output Statements including performance, efficiency and effectiveness in the use of public moneys, and

(f) such Value for Money and Policy Reviews as the Select Committee may select.

(4) Without prejudice to the generality of paragraph (1), the Joint Committee may consider the following matters in respect of the relevant Department or Departments and associated public bodies:
(a) matters of policy and governance for which the Minister is officially responsible,

(b) public affairs administered by the Department,

(c) policy issues arising from Value for Money and Policy Reviews conducted or commissioned by the Department,

(d) Government policy and governance in respect of bodies under the aegis of the Department,

(e) policy and governance issues concerning bodies which are partly or wholly funded by the State or which are established or appointed by a member of the Government or the Oireachtas,

(f) the general scheme or draft heads of any Bill

(g) any post-enactment report laid before either House or both Houses by a member of the Government or Minister of State on any Bill enacted by the Houses of the Oireachtas,

(h) statutory instruments, including those laid or laid in draft before either House or both Houses and those made under the European Communities Acts 1972 to 2009,

(i) strategy statements laid before either or both Houses of the Oireachtas pursuant to the Public Service Management Act 1997,

(j) annual reports or annual reports and accounts, required by law, and laid before either or both Houses of the Oireachtas, of the Department or bodies referred to in subparagraphs (d) and (e) and the overall performance and operational results, statements of strategy and corporate plans of such bodies, and

(k) such other matters as may be referred to it by the Dáil from time to time.

(5) Without prejudice to the generality of paragraph (1), the Joint Committee shall consider, in respect of the relevant Department or Departments—

(a) EU draft legislative acts standing referred to the Committee under DSO 114 and SSO 107, including the compliance of such acts with the principle of subsidiarity,
(b) other proposals for EU legislation and related policy issues, including programmes and guidelines prepared by the European Commission as a basis of possible legislative action,

(c) non-legislative documents published by any EU institution in relation to EU policy matters, and

(d) matters listed for consideration on the agenda for meetings of the relevant EU Council of Ministers and the outcome of such meetings.

(6) Where the Select Committee appointed by Dáil Éireann has been joined with a Select Committee appointed by Seanad Éireann, the Chairman of the Dáil Select Committee shall also be the Chairman of the Joint Committee.

(7) The following may attend meetings of the Joint Committee, for the purposes of the functions set out in paragraph (5) and may take part in proceedings without having a right to vote or to move motions and amendments:

(a) members of the European Parliament elected from constituencies in Ireland, including Northern Ireland,

(b) members of the Irish delegation to the Parliamentary Assembly of the Council of Europe, and

(c) at the invitation of the Committee, other members of the European Parliament.

(8) The Joint Committee may, in respect of any Ombudsman charged with oversight of public services within the policy remit of the relevant Department or Departments, consider—

(a) such motions relating to the appointment of an Ombudsman as may be referred to the Committee, and

(b) such Ombudsman reports laid before either or both Houses of the Oireachtas as the Committee may select: Provided that the provisions of DSO 111F apply where the Committee has not considered the Ombudsman report, or a portion or portions thereof, within two months (excluding Christmas, Easter or summer recess periods) of the report being laid before either or both Houses of the Oireachtas.
B) Powers of the Committee [derived from Standing Orders – DSO 85, 114 and 116 and SSO 71, 107 and 109]

The Joint Committee has:-

(1) power to take oral and written evidence and to print and publish from time to time minutes of such evidence taken in public before the Committee together with such related documents as the Committee thinks fit;

(2) power to invite and accept oral presentations and written submissions from interested persons or bodies;

(3) power to appoint sub-Committees and to refer to such sub-Committees any matter comprehended by its orders of reference and to delegate any of its powers to such sub-Committees, including power to report directly to the Dáil and to the Seanad;

(4) power to draft recommendations for legislative change and for new legislation;

(4A) power to examine any statutory instrument, including those laid or laid in draft before either House or both Houses and those made under the European Communities Acts 1972 to 2009, and to recommend, where it considers that such action is warranted, whether the instrument should be annulled or amended;

(4B) for the purposes of paragraph (4A), power to require any Government Department or instrument-making authority concerned to submit a Memorandum to the Committee explaining any statutory instrument under consideration or to attend a meeting of the Committee for the purpose of explaining any such statutory instrument: Provided that such Department or authority may decline to attend for stated reasons given in writing to the Committee, which may report thereon to the Dáil;

(5) power to require that a member of the Government or Minister of State shall attend before the Committee to discuss policy for which he or she is officially responsible: Provided that a member of the Government or Minister of State may decline to attend for stated reasons given in writing to the Committee, which may report thereon to the Dáil and Seanad: and provided further that a member of the Government or Minister of State may request to attend a meeting of the Committee to enable him or her to discuss such policy;

(6) power to require that a member of the Government or Minister of State shall attend before the Committee to discuss proposed primary or secondary legislation (prior to
such legislation being published) for which he or she is officially responsible: Provided that a member of the Government or Minister of State may decline to attend for stated reasons given in writing to the Committee, which may report thereon to the Dáil and Seanad: and provided further that a member of the Government or Minister of State may request to attend a meeting of the Committee to enable him or her to discuss such proposed legislation;

(6A) power to require that a member of the Government or Minister of State shall attend before the Committee and provide, in private session if so requested by the member of the Government or Minister of State, oral briefings in advance of meetings of the relevant EU Council of Ministers to enable the Committee to make known its views: Provided that the Committee may also require such attendance following such meetings;

(6B) power to require that the Chairperson designate of a body or agency under the aegis of a Department shall, prior to his or her appointment, attend before the Committee to discuss his or her strategic priorities for the role;

(6C) power to require that a member of the Government or Minister of State who is officially responsible for the implementation of an Act shall attend before a Committee in relation to the consideration of a report under DSO 164A and SSO 157A;

(7) subject to any constraints otherwise prescribed by law, power to require that principal office-holders in bodies in the State which are partly or wholly funded by the State or which are established or appointed by members of the Government or by the Oireachtas shall attend meetings of the Committee, as appropriate, to discuss issues for which they are officially responsible: Provided that such an office-holder may decline to attend for stated reasons given in writing to the Committee, which may report thereon to the relevant House(s);

(8) power to engage, subject to the consent of the Houses of the Oireachtas Commission, the services of persons with specialist or technical knowledge, to assist it or any of its sub-Committees in considering particular matters; and

(9) power to undertake travel, subject to—

(a) such recommendations as may be made by the Working Group of Committee Chairmen under DSO 108(4)(a) and SSO 104(2) (a); and
(b) the consent of the Houses of the Oireachtas Commission, and normal accounting procedures.

In accordance with Articles 6 and 8 of Protocol No. 2 to the Treaty on European Union and the Treaty on the Functioning of the European Union (Protocol on the Application of the Principles of Subsidiarity and Proportionality) as applied by sections 7(3) and 7(4) of the European Union Act 2009, the Committee has the power-

(a) to consider whether any act of an institution of the European Union infringes the principle of subsidiarity [DSO 116; SSO 109]; and

(b) to form a reasoned opinion that a draft legislative act (within the meaning of Article 3 of the said Protocol) does not comply with the principle of subsidiarity [DSO 114 and SSO 107].
C: Scope and context of activities of the Committee

In addition to the powers and functions that are given to Committees when they are established, all Oireachtas Committees must operate within the scope and context of activities in Dáil Standing Order 84 and Seanad Standing Order 70 as set out below.

- A Committee may only consider such matters, engage in such activities, exercise such powers and discharge such functions as are specifically authorised under its orders of reference and under Standing Orders;

- Such matters, activities, powers and functions shall be relevant to, and shall arise only in the context of, the preparation of a report to the relevant House(s).

- A Committee shall not consider any matter which is being considered, or of which notice has been given of a proposal to consider, by the Committee of Public Accounts pursuant to DSO 186 and/or the Comptroller and Auditor General (Amendment) Act 1993;

- A Committee shall not consider any matter which is being considered, or of which notice has been given of a proposal to consider, by the Joint Committee on Public Petitions in the exercise of its functions under DSO 111A(1); and

- A Committee shall refrain from inquiring into in public session or publishing confidential information regarding any matter if so requested, for stated reasons given in writing, by—

  (i) a member of the Government or a Minister of State, or

  (ii) the principal office-holder of a body under the aegis of a Department or which is partly or wholly funded by the State or established or appointed by a member of the Government or by the Oireachtas:

  Provided that the Chairman may appeal any such request made to the Ceann Comhairle, whose decision shall be final.