

The following statement was presented to the Oireachtas Joint Committee on Children, Disability, Equality and Integration for the meeting of the Committee on Tuesday 08 December 2020. The Psychological Society of Ireland (PSI) President Mr Mark Smyth addressed the Committee on behalf of the PSI, the Association of Occupational Therapists in Ireland (AOTI) and the Irish Association of Speech & Language Therapists (IASLT).

Opening Statement to the Joint Committee on Children, Disability, Equality and Integration

Report by the Ombudsman for Children entitled 'Unmet Needs' – a report on the challenges faced by the Children of Ireland who require an assessment of their needs

Madam Chairperson, members, on behalf of the Psychological Society of Ireland (PSI), the Association of Occupational Therapists in Ireland (AOTI) and the Irish Association of Speech & Language Therapists (IASLT), I would like to thank you for the opportunity today to address the Joint Committee on Children, Disability, Equality and Integration.

We welcome the opportunity to contribute to the discussion generated by the Report, from the Ombudsman for Children, entitled 'Unmet Needs' - a report on the challenges faced by the Children of Ireland who require an assessment of their needs.

Our representative bodies share the concerns of the Ombudsman in relation to the unacceptable delays that have been experienced by many children and families who have required an assessment of their needs. It is widely known at this point, and as so clearly outlined by the Ombudsman in his report, that there has been a long and sad legacy of assessments not being completed within specified statutory timeframes. This has resulted in parents and children enduring years of waiting lists, having to pay for expensive private assessments or trying to challenge the Health Service Executive (HSE) in the courts to have their children's needs identified. None of this is good enough.

To complete evidence-based assessments in a timely fashion, children's disability services and Assessment of Need (AON) should have been resourced with the required staffing. Instead of providing the staffing required, the HSE has embarked on an alternative, less widely publicised pathway that we wish to draw to the attention of the Committee, which we believe is of great concern.

In January 2020, the HSE implemented a new Standard Operating Procedure (SOP) for AON across the country. Whilst our professional bodies are supportive of an SOP in principle, we have significant concerns regarding the procedure in its current iteration. All of these concerns were relayed to the Oireachtas Joint Committee on Health in June 2018 and were reflected in the final report by the Committee on the matter. Our three organisations subsequently published a statement welcoming the report of the Oireachtas Committee. These concerns were also recently reiterated by Consultant Paediatricians working in neurodisability in Children's Health Ireland.

The implementation of the new SOP has proceeded despite PSI, AOTI and IASLT clearly stating that it is not in the best interests of children and, we would contend, without in any way acknowledging the recommendations of the Oireachtas Committee. Furthermore, the commitment to meaningful engagement with professional bodies to address our concerns, given by the HSE to the Oireachtas Health Committee in 2018, was not honoured.

It remains our considered opinion that the changes to clinical practice described within the SOP will in many cases prove detrimental to children and their families. Our members are also concerned that compliance with the SOP could lead to them being in breach of their professional body and CORU codes of conduct and ethics. The SOP is neither evidence-based nor based on good practice in assessment of children with disabilities.

A summary of our concerns is as follows:

- 1. It is our opinion that the Preliminary Team Assessment (PTA) model embedded within the SOP which is currently being implemented by the HSE is contrary to the spirit of the Disability Act (2005), which was developed as rights-based legislation. The PTA is a brief screening assessment. Its introduction has significantly reduced the level of assessment provided to a child under the statutory framework of AON. Prior to the SOP, the child's needs determined the level and type of assessment provided. These assessments varied substantially because children's needs vary. However, the SOP replaces this with a uniform screening assessment, to be completed by two clinicians in a maximum of 90 minutes, regardless of the child's presentation and needs;
- 2. The new SOP does not facilitate the diagnosis of, for example Autistic Spectrum Disorder or Intellectual Disability and will no longer be provided as a part of the AON protocol. Instead children will be identified as 'health needs' in the service statement. However, the independent Disability Appeals Officer has found against the HSE on several occasions for failing to provide a comprehensive AON, including failures to address the specific concerns of the applicant relating to diagnostic assessment, as required by the Health Information and Quality Authority (iHIQA) Standards;
- 3. The Disability Act states that an assessment report shall state whether the applicant has a disability, state the nature and extent of any disability, and describe both the health and education needs occasioned by the disability and the health or education services required to meet those needs.

It is our view that in the vast majority of cases it will not be possible for a psychologist, occupational therapist or speech and language therapist to answer these questions and feed these back to parents within the maximum timeframe permitted within the SOP (90 minutes). 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, in accordance with <u>Informing Families of Their Child's Disability: National Best Practice Guidelines.</u>

- **4.** In our opinion the HSE's introduction of the PTA in place of comprehensive assessments will give rise to the following risks:
 - a. A child may be deemed likely to have a disability but require further comprehensive assessment to determine the nature and extent of their disability. However, as the child will already have completed their Assessment of Need (as defined in the SOP and not the Disability Act) there will be no defined legal timeframe within which this further assessment must be carried out. Children will then have to go on a new waiting list to await more comprehensive professional assessment;
 - b. A child may incorrectly be deemed not to have a disability, as the disability was not apparent during the brief 90-minute screening. The absence of evidence in a single screening session and setting is insufficient evidence to warrant a determination of the absence of a disability. If a child receives an incorrect determination of no disability, they will consequently be denied more comprehensive assessment, and receive either no or inappropriate intervention;
 - c. A child's difficulties may be incorrectly outlined due to a comprehensive assessment not being permitted within the PTA model.

In many geographical areas each of these scenarios will result in very substantial delays for many children and their families in accessing a wide range of appropriate and needs-based financial supports, educational provision, and health services. In addition, in many cases children risk being placed on potentially inappropriate, and long, waiting lists for assessment or intervention.

Our members have reported that since the implementation of the PTA this month the outcome in almost all cases to date has been a recommendation for further assessment. It is crucial to note that this further assessment will not occur within the legislative framework of the Disability Act and therefore there are no statutory requirements for them to be completed within an acceptable timeframe. It is also important to consider that this is only to complete an assessment to identify needs, this is not the same as receiving intervention, which should follow assessment.

Furthermore, the Disability Act does not entitle children with disabilities to services to meet needs identified through the Assessment of Need process. Having often waited for very lengthy periods of time for full assessment to be completed, children with identified needs then must go on a new waiting list to receive Psychology, Occupational Therapy, and Speech and Language Therapy

services. The wait time for these services can be months to years depending on geographical location.

The report by the Ombudsman for Children has highlighted the challenges faced by the children of Ireland who require an assessment of their needs. Rather than seek to address those challenges, the primary goal of the new SOP would appear to solely be to enable the HSE to meet its statutory obligations under the Disability Act.

In order to achieve this goal, the SOP seeks to replace a comprehensive professional assessment process with a uniform brief screening session, and to designate diagnostic assessments as 'health needs'. We are already seeing the entirely predictable result, where the assessment of a child's needs indicates that the child needs an assessment.

The original mistake made in developing the AON process was in separating assessment from intervention. Assessment and intervention should be part of a seamless service offered to children with difficulties. This flaw in the system is now further compounded by the PTA.

Four case vignettes attached to this document briefly illustrate what is now happening on a daily basis across the country.

The implementation of this new approach will exacerbate an already intolerable situation for the children of Ireland and their families. The Psychological Society of Ireland, the Association of Occupational Therapists of Ireland and the Irish Association of Speech & Language Therapists seek the support of the Committee in recommending an immediate cessation of the SOP. We also seek the Committee's support in recommending the HSE take a standards-based approach grounded in good practice models of professional assessment of children with disabilities. We are happy to take questions from the Committee in relation to any of this.

Thank you.