The Psychological Society of Ireland
Cumann Síceolaithe Éireann

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Dear Michael,

Please find attached the PSI submission on the HSE ASD Diagnostic Protocol Draft.

The PSI welcomes the opportunity to contribute to this review. We would welcome an opportunity to meet with your review group to outline the thinking behind our submission. As the only professional membership body representing psychologists in Ireland, we believe that it is imperative that our views influence and are incorporated into the final protocol.

We look forward to further dialogue in due course.

Sincerely,

B O'Connell　　　　Terri Morrissey

Brendan O Connell
President
Psychological Society of Ireland

Terri Morrissey
Chief Executive Officer
Psychological Society of Ireland

What is helpful about this draft protocol?	• Ethos of decreasing wait times to provide timely access to diagnostic assessment is laudable • Communication, Accessibility, and Early intervention sections are welcome • There is value in providing families with access to ‘pre-diagnostic assessment intervention’ (page 15). Generic interventions such as Hanen, Parents Plus, Triple P etc. could be very helpful while families are awaiting diagnostic assessment • Tier 2 and Tier 3 diagnostic assessments could be deemed in line with PSI Guidelines on Autism assessment if modified to include standardised assessments allowing for the developmental assessment of a child’s strengths and needs
What are the limitations of the proposed protocol for diagnosing ASD?	Tier 1 has multiple deficits 1. Brief screening is insufficient to provide a clinical diagnosis of Autism Spectrum Disorder a. Alternative explanations for the presentation need to investigated and ruled in/out b. Co-existing conditions, e.g. what level of intellectual disability if present, anxiety disorder, attention deficit hyperactivity disorder, etc. need to be determined simultaneous to the ASD findings for parents to understand the realities of their child’s disability, and of course, to direct to the proper service provider and school placement. An ID may in fact be the primary diagnosis and ASD secondary. This knowledge is needed from the start c. Observing the child in a natural setting is required. This does not appear to be factored into the time allotted for a “Tier 1” assessment as only 1.5 hours in total is suggested d. ASD can be missed without a thorough assessment when symptoms are subtler and/or the assessor(s) have limited experience with the wide range of presentations, differences in age groups and between the genders. This has serious implications in terms of potential negligence e. Psychologists use both standardised and non-standardised measures to develop a holistic formulation of a child and family's needs in the assessment process for every child. Psychologists also need to be able to take accountability for each component of the assessment process. Tier 1 assessments as proposed does not give sufficient time to properly make a diagnosis f. DSM-5 requires a statement of whether an individual with ASD has an accompanying intellectual disability, or language impairment. Unless a pre-existing and recent cognitive assessment, assessment of adaptive behaviour and speech and language assessment have been completed and are available for review, it would not be possible to make such a statement

	g. The AON summary report requires the assessor to state whether or not the child has difficulties in communication, learning, mobility or significantly disordered cognitive processes; a Tier 1 assessment is wholly inadequate for the purposes of forming a valid opinion on these areas in most cases h. Families are appreciative when time is taken. They can become confused, upset and/or believe their child wasn't fully understood or evaluated when a diagnosis is given in a short time i. The therapeutic process underpins the diagnostic assessment and required 'holding' of each family during that process are important omissions j. In the absence of assessment to profile a child's developmental level, strengths and needs, it would be extremely risky to make recommendations in relation to autism specific preschool or school placement k. Consultation with multi-disciplinary colleagues needs to be accommodated with regard to the time line. The draft protocol states that a Tier 1 assessment will be conducted by two team members. It does not specify anything about the parameters for making that selection. All clinicians would need to be capable of ASD assessment, differential diagnosis, and mental health assessment. This precludes some disciplines under Tier 1 l. The draft protocol suggests that children and families would be provided with 'pre-diagnostic assessment interventions' (page 15) or a 'preliminary family support plan' (page 25). The provision of appropriate interventions is based on a full understanding of a child's functional and diagnostic difficulties which cannot be achieved with a Tier 1 assessment 2. Anything short of a full assessment as recommended by Best Practice: a. Can easily lead to inappropriate intervention planning and potential clinical risk where significant clinical needs for the child and family are not identified, such as child welfare/protection/ parental mental health as well as wider developmental and medical risks. b. There is a danger that a rush to confirm or disconfirm a diagnosis could result in serious misunderstandings of the needs of very vulnerable children. Such cases present to all children's services. Indeed, many children who are in the care of the State or are otherwise clients of Tusla routinely present to primary care services, and not necessarily to CAMHS or disability teams c. There is no mechanism for exploring family concerns in a paced manner relative to their emotional presentation and history d. May lead to issues with parents having difficulty accepting and adjusting to the diagnosis which can in turn contribute to poor developmental and emotional adjustment outcomes for the child and ongoing emotional stress for the parents

   e. Separating diagnosis from the assessment and understanding of the needs of the child are key omissions from the draft proposal
   f. There is a statement that the team providing the Preliminary Team Assessment are required under the Disability Act (2005) to state whether it is likely or not that the child/young person presents with a disability (p45). However, section 8(7) of the Act itself states that the assessment must make a determination in relation to 'whether the applicant has a disability'. Thus, the Act requires a definitive statement, rather than an opinion of likelihood
   g. The protocol goes on to say that if a young person is deemed to require further input from the Children's Disability Service, "it is reasonable to assume that s/he will be deemed to have a disability". The recommendation for further assessment inherently indicates that it was not possible to make a determination about the existence of a disability

3. Matching clinicians' competence with diagnostic assessment intensity.
   a. This is impossible, at least at this time, due to under-resourcing and lack of valid, standardized measures to assess clinical competence in diagnosing ASD. Unions could become involved and lawsuits could ensue
   b. Clinical judgment in providing a diagnosis is based on the clinician demonstrating relevant evidence of a comprehensive assessment, including standardized assessment as well as referencing the DSM-5
   c. The proposal will place psychologists and other disciplines who are not professionally qualified to provide a diagnosis of ASD (e.g. SLTS, OTs, nurses) under significant pressure to work outside of their clinical competencies and further to do so without relying on sufficient/thorough assessment strategies
   d. Clinicians without competency in diagnosing ASD will not have the opportunity to become competent without conducting full, i.e. proper assessments, until they become competent. There are no shortcuts to this learning
   e. The protocol states that if a cognitive assessment is needed it will be carried out by a Clinical or Educational Psychologist (page 31). This should refer to 'a Psychologist who is trained and competent to administer' any needed tests, without any reference to clinical specialism

4. The document states: *ASD can be diagnosed in children as young as 3 years*
   a. We can diagnosis children younger than 2 based on emotional and behavioural presentations that cannot be accounted for by any other reason. This is CRITICAL as the best outcome is with children under the age of 3

	b. This is not an age at which you want to see a diagnostic error. The clinician must be free to take the time necessary to insure ASD is the most plausible explanation 5. Assessment tools used to diagnose autism a. The list provided is incomplete b. Caution around such lists as new measures may emerge and others fall out of favour while this HSE document is in place c. The document states that any cognitive assessment should use the WISC-V or the WAIS-IV. The majority of assessments are completed with children under the age of 6, so neither of these instruments would be applicable, nor for non-verbal children or those with a significant intellectual disability d. Clinicians must be free to follow the protocol and choose the tools they believe are best suited to the child being assessed 6. Re: privately sourced diagnostic reports (e.g., as contracted by the HSE or independently by parents) minimum requirement for acceptance of such reports is that there is input from at least two disciplines (e.g., a Psychologist or a Psychiatrist, and a Speech and Language Therapist) a) ASD is a DSM-5 and ICD10 Condition, as such, the only professionals qualified to make this diagnosis are Medical Doctors, Psychiatrists and Psychologists b) Nonetheless, we agree that a ‘team’ approach is the best way to secure a confident and thorough assessment of the child c) Other disciplines are required for assessment for programme planning and intervention purposes, but not diagnosis. We all remain within our own professional boundaries in terms of assessment and diagnoses. d) This item is relevant to ‘clinical competencies’. You could have one highly experienced and competent Psychologist or two inexperienced and not yet sufficiently competent other clinicians, so there is not necessarily safety in numbers e) Requiring more than one clinician also imposes yet additional emotion time, and financial stress on parents who only go the private assessmer route when there is an unacceptably long wait in the HSE.
What alternative approaches might address these limitations (in the context of having to achieve the principles outlined in Table 4)?	• There is no short cut to diagnosing a complex condition such as Autism • We propose that the solution is for the HSE to hire more suitably qualified and trained Psychologists, Psychiatrists and Developmental Paediatricians to do the job properly, it cannot be done within the current available resources. The current wait lists across the country are testament to this An audit of the numbers of clinicians required to meet the wait list and ongoing demands should be completed, published, and used to guide resourcing within the HSE

Additional comments	• There are many potential conflicts arising in relation to the Preliminary Team Assessment in Primary Care or Secondary Care model as outlined in the document with regard to the obligations of accuracy, therapeutic safety and established best practice. In reviewing the stated goals for this document, it appears one takes priority: *"To maximise the efficient use of existing HSE and HSE-funded services in assessing for ASD".* This however places Psychologists at odds with their own professional code of ethics, the PSI policy document on the Assessment of ASD (2016), as well as the NICE guidelines so they are not feasible to implement. Psychologists do not take clinical direction on how to conduct a diagnostic assessment of a complex condition from administrators /management directive, but from their professional bodies. The fact that this document was devised in the first place without consulting the Psychological Society of Ireland is of serious concern • The proposals are being made alongside an awareness of the chronic under-resourcing of HSE services, particularly primary care services. The incorporation of assessments as suggested into the work of primary care clinicians would have the serious effect of limiting the range of services available to the public through primary care, as well as compromising the integrity of the work that has been done • The draft protocol states that one of the objectives is to provide equity of access for all who seek a diagnostic assessment for ASD. However, due to national differences in how services are structured and resourced, this objective would very likely not be achieved • Primary care services are developed to different extents in different regions. In many areas, primary care networks do not operate in such a way that it is supportive of multidisciplinary working as described in the document. There is a danger that rolling out such standards in the absence of appropriate resourcing and service development will further limit the integrity of ASD assessment • The draft document makes specific reference to the role of CAMHS in ASD assessment, but omits reference to the draft national shared protocol between HSE disability primary care and CAMHS services, which contains specific protocols for shared assessment and care pathways