

Amaze submission to draft national diagnostic guideline for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia.

Submissions required to be submitted via the online portal, following the format below, addressing one or more of the chapters in the draft guideline. The chapters addressed in this submission are highlighted in red.

Submitted by Nicole Antonopoulos 18 October 2017

What aspects of the guideline (including supporting documents) would you like to provide feedback about?

- Acknowledgements
- Foreword
- Overview
- ASD Assessment Guiding Principles
- ASD Assessment Scope
- ASD Assessment Roles
- ASD Assessment Settings
- Initiating an ASD Assessment
- Diagnostic Evaluation
- Functional and Support Needs
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Forward

Amaze welcomes the opportunity to comment on the Cooperative Research Centre for Living with Autism's ('Autism CRC') draft national guideline for community consultation, titled '*The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia*' ('draft guideline').

As the peak body for autistic people and their families in Victoria, we strongly support the development of a national guideline capable of supporting all consumers to access timely and reliable diagnostic, and functional and support needs assessments.

The autistic community and their families/carers regularly share with Amaze their experiences in accessing an Autism Spectrum Disorder (ASD) diagnosis. The barriers that are repeatedly shared and need to be addressed are:

- Lack of understanding of autism and its presentations by primary healthcare professionals such as local General Practitioners and Maternal and Child Health nurses;
- Lack of understanding of presentation of girls on the autism spectrum;
- A reluctance of paediatricians and paediatric psychiatrists to diagnosis autism under the age of three;
- Waiting lists for accessing diagnosis through the public health care systems;
- Limited access to diagnosticians in regional areas;
- Financial constraints for those seeking diagnosis through private diagnosticians, generally not wanting to wait for the public system;
- Lack of clear and concise information and support for families in navigating the diagnosis pathway;
- Having to fight the system to get a diagnosis, and getting confirmation of what they already suspect requires a great deal of persistence.

In 2016, Amaze conducted a survey of the Victorian autism community on a range of subjects, including their experiences of assessment and diagnosis and the need for consistent approaches across sectors, including in schools and for accessing services and supports. The following comments received through this survey further illustrate this experience.

We had to wait six months to see the specialist for diagnosis. Once we saw him he had confirmed diagnosis within a week. Six months on a new patient list is a long time when you need help.

No one could tell me how to go about getting diagnosis, it was by chance and pure luck we ended up getting in to see someone who was able to diagnose without too much difficulty after spending months trying to work through OT's and having other assessments done first.

There seems to be low awareness of how ASD presents in girls, preventing early diagnosis and meaning that girls miss out on funding.

I was initially frustrated with our first paediatrician due to her mentioning autism but not being willing to diagnose due to her age. It wasn't until we were lucky enough to get into our second paediatrician that we got the diagnosis she needed.

The public waitlist was nine months so we paid privately over \$1000 so we didn't miss out on early intervention. It was difficult to watch other people wait who couldn't afford it.

(Diagnosis) just took too long and too many misdiagnoses along the way.

The waiting list for the public system is too long! It should be done within weeks of a referral not months and months! Waiting times for appointments are far too long! For one appointment I had to wait 4 hours to be seen!!!!

We had to travel to Melbourne (from Bendigo) to get assessments done - otherwise we would have waited 2-3 years or longer.

Using inexperienced and unsupervised paediatric fellows as the first line of enquiry through the public system is hit and miss. You really need experts to assess kids.

Diagnosis is important as it gives the child or young person a vehicle to reach their potential and independence. Parents are not listened to enough!

Many of these experiences were also shared with the Victorian Parliament during its recent Inquiry in services for people with ASD (see Final Report from this inquiry at <https://www.parliament.vic.gov.au/fcdc/inquiries/inquiry/400>), leading to a number of recommendations to improve access to reliable ASD diagnosis in Victoria (discussed below).

These experiences also are consistent with those highlighted in your recent research paper titled, *ASD diagnosis in Australia: Are we meeting best practice standards*.

ASD Assessment Guiding Principles

We agree that ASD Assessments should be guided by the principles of an individual and family centred, holistic, strengths focussed and evidence based approach. It is of the utmost importance that consumers and their families/carers are at the centre of all ASD assessment processes and decision making.

It is also vital that the voices of autistic people, and those that support them, are central to the development of this diagnostic guideline. Accordingly, we welcome the extensive amount of work by the Steering Committee and research team to date, including extensive community consultations, to ensure the voices of autistic people and those who support them have been heard.

Clinicians experienced in the diagnosis of autism must also have a strong voice in the guideline's development to ensure that it is meaningful, practical and has the utmost utility for diagnosticians diagnosing ASD on a day to day basis. Without this utility for diagnosticians, the guideline will be unable achieve the impacts sought.

The development of this guideline must also be driven by the principle of equity: aiming to ensure that all Australians, regardless of age, gender, race, or geographical location can access timely, rigorous and reliable diagnostic, and functional and needs assessments. Consistency in diagnostic decision making and functional and support needs assessments, across all Australian states and territories, is essential.

Assessment roles

Amaze understands there are a range of views among individuals and organisations that have been involved in the development of this guideline, regarding the type and breadth of professionals that should qualify as Diagnosticians and Functional and Support Needs Assessors (FSNAs)

We are of the view that the professionals identified in the draft guideline bring a valuable range of skills to the assessment of ASD and functional and support needs. However, we are concerned that the allied health professions identified will be unable to bring the breadth and depth of diagnostic skills required of a diagnostician, to undertake a holistic assessment of a consumer's presentation. As recognised in the draft guideline, when identifying an 'Holistic Framework' as a guiding principle of ASD assessment (Chapter 4), ASD assessments must not occur in a vacuum. They must appraise the full range of clinical symptoms, consider the environmental context and focus on the consumer's unique challenges and strengths, rather than simply matching an individual to a diagnostic category.

As also recognised in the draft guideline, under 'Important Consideration' (Chapter 12), the diagnostician must consider whether a person may be presenting with intellectual disability, differential conditions (including genetic, psychiatric and neurodevelopmental conditions) and/or co-occurring conditions (including psychiatric, neurodevelopmental, neurological, medical and genetic conditions known to co-occur with ASD at higher than expected rates). We are concerned that the allied health professionals identified do not have the breadth or depth of training, or subsequently the skills or experience required to undertake an holistic assessment (or in particular, assess the possibility of intellectual disability or these differential or co-occurring conditions).

Reliability and accessibility

The guideline must promote rigorous and reliable ASD assessments by highly skilled and experienced professionals, while also ensuring timely access for all consumers to diagnosis, and functional and support needs assessments.

We therefore welcome the prescription in the draft guideline regarding the necessary high level of skills and experience each professional must demonstrate to undertake ASD diagnosis and functional and support need assessments. However, it will be important to ensure timely access to these assessments for all Australians, regardless of whether they live in the city or rural or remote areas. As recognised in the draft guideline and your research report titled *ASD diagnosis in Australia: Are we meeting best practice standards*, there is considerable evidence that people living in regional and remote locations currently experience poor access to diagnostic services and receive ASD diagnosis later than people living in urban communities.

Widening the type of professionals that may undertake an ASD diagnosis or functional and needs assessment has the potential to increase accessibility. However, it is also important to ensure that the skills and experiences prerequisites can be met by sufficient numbers of professionals, ensuring that the guideline does not actually reduce the number of professionals across Australia that may undertake these roles, thereby reducing access and/or leading to lengthy waiting lists for services (particularly in rural and remote areas). As also recognised in your research report referenced above, there are currently lengthy waiting lists across Australia, particularly for public services relative to private services.

We therefore encourage you to gain an understanding of current numbers of professionals that would meet these requirements. We understand from your Technical Report that feedback will be sought from Diagnosticians who are early adopters of the guideline recommendations, to determine if recommendations need to be modified or if additional recommendations should be included. We also understand that you have submitted a funding request to the Commonwealth government to conduct a project that evaluates the extent to which guideline recommendations are adopted into routine practice. It will be important that this project evaluate the numbers of diagnosticians and FSNA's available across the country and map their locations.

A national register of diagnosticians and FSNA's would also be valuable, ensuring transparency and assisting consumers to find qualified professionals for ASD assessments. A national register could also provide a system of oversight to ensure that professionals undertaking diagnosis, and functional and needs assessments do in fact meet the skills and experiences prerequisites. As a prerequisite to registration, professionals could be required to declare their skills and experience. Registrations could be reviewable annually, ensuring requirements for ongoing professional development are also met.

If there is a need to increase the numbers of professionals meeting the prerequisites, particularly in rural and regional areas, the Commonwealth government should be proactive. This is particularly important in the context of the National Disability Insurance Scheme where autistic people are already facing significant difficulty accessing therapy and other services. The government should be encouraged to take a holistic approach to how it will increase access to diagnosticians, FSNA's and service providers. For example, elements of block funding may be required in certain areas to maintain services, incentives for rural and remote professional placement may be required and existing diagnosticians and FSNA's must be supported to facilitate peer to peer training for future diagnosticians and FSNA's.

Telehealth

The inclusion of telehealth as an acceptable method for consumer interview and observation will assist in meeting the needs of people in areas where the number of professionals with the prerequisites for diagnosis, and functional and support need assessments are not available.

However, as recognised in your Evidence Table 31, further research is required to support the reliability of telehealth to diagnose ASD and to investigate the best systems and processes for providing telehealth support. However, learnings may be taken from programs to advance telehealth in other areas of healthcare, such as the VidKids program - a telehealth program piloted by a consortium led by Vision Australia, to provide diagnosis and other supports to children with hearing or vision loss in remote and outer regional areas. The project was aimed at delivering qualified allied health and education services where such expertise may otherwise have been scarce. For more information, see <http://www.visionaustralia.org/services/children/vidkids> and <http://www.healthinonet.ecu.edu.au/key-resources/programs-projects?pid=1354>. A range of other telehealth models have also recently been reviewed in Australia - see for example 'One in Four Lives: The Future of Telehealth in Australia' available at https://www.adma.org.au/.../doc.../158-one_in_four_lives_white_paper_v7.html and the Strategic review of telehealth in NSW: Final report available at www.health.nsw.gov.au/telehealth/Documents/strategic-review-of-telehealth-in-NSW.PDF.

Commonwealth government funding for ongoing evaluation will need to be sought to identify which telehealth methods for ASD diagnosis and functional and support need assessments are proving feasible for consumers, their families and professionals, any barriers to sustainability and to measure the reliability of assessments across the various telehealth models. Professional training for undertaking diagnosis and functional and support need assessments via telehealth models should also be prioritised.

Recommendations:

- Review the professionals eligible to perform the role of a diagnostician under the guideline, particularly speech pathologists and occupational therapists.

- To ensure the sustainability of the guideline, Commonwealth funding should be sought/utilised to:
 - evaluate the numbers of diagnosticians and FSNA's in Australia that meet the prerequisites for diagnosing ASD and assessing functional and support needs, and map their locations.
 - Develop a national register of diagnosticians and FSNA's, with a requirement that professions declare their skills and experiences; and
 - identify which telehealth methods for ASD diagnosis and functional and support needs assessments are most feasible for consumers, their families and professionals, any barriers to sustainability and measure the reliability of assessments across the various telehealth models.

ASD assessment settings

Amaze agrees that ASD assessment should involve the collection of information about an individual's behaviour in at least two settings relevant to the individual's daily life, ideally through direct observation by the Diagnostician, but also through secondary reports provided by the caregiver and/or Professional Informant(s). As recognised in your Evidence Table 28, there is consistent evidence that ASD diagnostic assessments should be conducted across the multiple settings identified in the draft guideline.

Initiating an ASD assessment

Amaze welcomes the guidance provided in the draft guideline regarding screening tools and the additional factors to consider in determining whether to refer for an ASD assessment. This guidance will need to be accompanied by structured training and information resources to develop the ASD knowledge of General Practitioners and others involved in initiating an ASD assessment, such as Maternal and Child Health Nurses (as per recommendation of the Victorian Parliament in its Final Report to its Inquiry into services for people with ASD, recommendations 3.1 – 3.2).

Autistic females

As discussed below under "Important Considerations", we are concerned about the historic failure of general practitioners and other professionals engaged in initial assessments/screening to recognise the symptoms of ASD in girls and women.

A core aspect of this failure has been the lack of awareness among general practitioners, and others involved in initial ASD screenings, of the different presentation of ASD characteristics in females. In particular, these professionals are often unaware of the potential for females to go to great efforts to mask or hide their autistic characteristics during an ASD assessment, and in everyday life.

The historic failure to diagnose ASD in girls and women has also been compounded by the limited reliability of many developmental screening tools for screening ASD in girls and women. There is evidence that commonly used ASD screening and diagnostic tools (such as the Autism Diagnostic Observation Schedule [ADOS] and the Autism Diagnostic Interview–Revised [ADI-R]), reflect a presentation more commonly found in males than females, and may lack the sensitivity and specificity required to identify autistic characteristics in females (See for example, Lai, M., et al 2015. Sex/gender differences and autism: Setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry*, vol. 54, no. 1, pp. 11-24, available at

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4284309/>; Rynkiewicz, A., et al 2016. An investigation of the 'female camouflage effect' in autism using a computerized ADOS-2 and a test of sex/gender differences. *Molecular Autism*, vol. 7, no. 1, pp. 1-8, available at <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-016-0073-0>

Recommendations:

The new diagnostic guideline must prioritise an increase in the reliability of initial autism assessments/screening in women. Accordingly, we recommend that:

- Gender be included in Table 5: Additional factors to consider in determining whether to refer for an ASD assessment. Within this table, the different presentation of ASD characteristics in girls and women, and likelihood of girls and women masking their autistic characteristics should be highlighted;
- The guideline highlight the limited reliability of standardised developmental screening tools for girls and women in Chapter 8.1.2, regarding the Evidence of Signs and Symptoms.

Diagnostic evaluation

Amaze supports the two-tiered approach to diagnostic evaluation outlined in the draft guideline. We agree that a simplified assessment process (Tier 1) is required in cases where an ASD diagnosis can be confirmed or ruled-out with certainty. We also agree that a diagnostic evaluation incorporating a multidisciplinary assessment team (Tier 2) is required in cases where an ASD diagnosis cannot be confirmed or ruled-out with certainty.

Diagnostic criteria (DSM-5).

An understanding of the diagnostic criteria under DSM-5 and its application must be at the core of any ASD diagnosticians' decision making processes. These criteria contained in the DSM-5 are two-fold. Firstly, a diagnostician must assess whether the consumer meets each criterion for an ASD diagnosis. Secondly, if the consumer is assessed as meeting the criteria, the diagnostician must assess the severity level of their deficit under each criterion, from Level 1 (requiring support) to Level 3 (requiring very substantial support).

While the draft guideline outlines the first part of the criteria (for assessing whether a consumer meets the criteria for an ASD diagnosis) it does not outline the second part of the criteria for determining the consumer's severity level. This second aspect of the criteria must be included in the guideline to guide complete assessments by diagnosticians, and assessment of severity when applying your ASD Combined Assessment Report Template DSM - 5. It is also important in the context of the NDIS as we understand that the assessed severity level under DSM-5 can have a significant impact on access to the scheme (with consumers with Level 1 severity assessments often having to provide further information to access the scheme). We also understand that it has a significant impact on services and supports allocated to participants in their support packages, with the severity level impacting the identification of the participants reference group and associated typical support package (under the current NDIS First Plan approach).

Reliability and Accessibility

The principle of equity must lead the development of the diagnostic evaluation process, ensuring that it promotes timely and low cost access to a reliable diagnostic evaluation for all. Reliable diagnostic evaluations are essential to instilling consumer confidence in the process, as well ensuring

the cost-effectiveness of supports provided under the NDIS for governments and the broader community.

Diagnostic evaluations must be affordable. As your survey of public and private health professionals in 2015 found, there currently exists considerable variability in the cost of ASD assessments, with costs to individuals/families ranging from \$0 in the public sector to up to \$2750 in the private sector (Autism CRC 2016. ASD diagnosis in Australia: Are we meeting best practice standards). We therefore welcome a tiered process that has the capacity to increase efficiencies in the diagnosis of ASD in very obvious cases, reducing the current strain on public resources and costs to consumers. However, it is equally important that Tier 2 assessments (including in particularly complex cases) can be accessed by consumers of all socio-economic backgrounds and are cost-effective to diagnosticians and government. A failure to make Tier 2 assessments accessible will continue to cause consumers with more subtle symptoms to be undiagnosed or diagnosed later in life. They will also fail to receive the supports needed, which the evidence clearly shows will lead to increased social and economic costs later in life. An inaccessible Tier 2 process may also lead to gender discrimination (with females incurring higher costs than males) given females may be more likely to appear with a less obvious presentation of autism and be referred to Tier 2 compared to men (see discussion below under “Important Considerations”).

It follows that the proposed approach will only be sustainable and capable of ensuring reliable ASD diagnosis for ALL consumers, if a sustainable nationwide diagnosis system and funding model is developed to support it. We understand from your Technical Report that a funding request has been submitted to the Commonwealth government to conduct a project that evaluates the extent to which guideline recommendations are adopted into routine practice, including to estimate the costs for each stage of the ASD assessment. We would also encourage you to engage or if necessary, seek subsequent funding, for a cost-benefit analysis of Medicare funding all or a significant share of ASD assessments and diagnosis (weighing the social and economic costs of failure to diagnose and lack of quality and reliability of diagnosis).

A nationwide, Commonwealth government funded, ASD diagnostic service would also support equal access for all Australians, ideally coordinating screening, diagnosis, professional training and post diagnosis support (compare state-wide ASD diagnostic service recommended in the Victorian Parliament in Final Report to the Inquiry on services for people with autism, recommendation 3.7 – 3.8). As discussed below, functional and needs assessments should be separately funded under the NDIS.

Diagnostic evaluations must be reliable and consistent across and within Tier 1 and 2. The ongoing monitoring and evaluation of ASD assessment quality should be prioritised going forward, with Commonwealth funding to audit and evaluate ASD assessments.

Autistic females

Drawing on the discussion above regarding the assessment of ASD in females under ‘Initiating an ASD assessment’, we recommend that this chapter highlight the importance of diagnosticians taking into account the different presentation of ASD in females when undertaking an ASD assessment, particularly the potential for women and girls to mask their autistic characteristics.

It should also highlight the limitations of ASD assessment criteria in identifying ASD in women and girls. The latest revision of the criteria for diagnosing ASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), is accompanied by a statement that girls with autism might not be diagnosed due to gender differences, and that “girls without accompanying intellectual impairments

or language delays may go unrecognized, perhaps because of subtler manifestations of social and communication difficulties". At the very least, this statement should be quoted in the guideline. However, studies to date have failed to find that the application of the DSM-5 criteria identifies autistic females any more (or less) reliability than DSM-4 (see Haney J 2015. Autism, Females, and the DSM-5: Gender Bias in Autism Diagnosis. October 2015. Social Work in Mental health. Available online via https://www.researchgate.net/publication/283467413_Autism_Females_and_the_DSM-5_Gender_Bias_in_Autism_Diagnosis)

Recommendations:

- Amend Chapter 9.2 of the draft guideline, to include the criteria for assessing severity level in the outline of the DSM-5 criteria.
- Review funding model and undertake a cost-benefit analysis of nationwide ASD diagnostic service and Medicare funding all or a significant share of ASD assessments and diagnosis.
- Commonwealth funding be sought for ongoing audits and evaluations of the quality of ASD assessments under the guideline.
- The guideline highlight, in this chapter, the importance of diagnosticians taking into account the different presentation of ASD in females when undertaking an ASD assessment, particularly the potential for women and girls to mask their autistic characteristics. It should also highlight the limitations of ASD assessment criteria in identifying autistic females.

Functional and support needs assessment.

Amaze supports the approach outlined in the draft guideline for functional and support needs assessments to be undertaken by prescribed professionals, with prescribed high level skills and expertise, in parallel with diagnostic evaluations.

In the context of the NDIS, we have been concerned about the conduct of functional and needs assessments by planners that are inexperienced in the application of these tools and fail to understand matters that may confound a participant's responses. Autistic people can often have difficulty processing the meaning or intent of questions in assessment tools and can struggle to provide a fully informed or accurate response in high pressured situations, such as a planning meeting.

Functional Assessment Tools

We appreciate the value of valid, reliable, accurate and efficient functional assessment tools capable of measuring levels of functioning in people diagnosed with ASD. We also welcome the recommendation that a Functional Assessment should determine the individual's activity related and character strengths.

However, we are concerned that the draft identifies functional assessment tools [such as Paediatric Evaluation of Disability Inventory - Computer Adaptive Test ('PEDI-CAT') for children, adolescent and young adults, and the World Health Organization Disability Assessment Schedule 2.0 (WHODAS) for all ages] as tools with a strong evidence-base for use with autistic people.

There is evidence that commonly used functional assessment tools, including the PEDI-CAT and WHODAS may not be providing a valid, reliable or accurate measure of the nature, frequency and intensity of young autistic children's diverse support needs (particularly between the ages of 0 to 5) and indeed, may be providing a barrier to young autistic children accessing the levels and types of early intervention they require, via the NDIS Early Childhood Early Intervention ('ECEI') pathway (see

Coster W et al 2016. Evaluating the appropriateness of a new computer-administered measure of adaptive function for children and youth with autism spectrum disorders. *Autism*. Vol. 20(1), 14 – 25; Kao YC et al 2012. Comparing the functional performance of children and youth with autism, developmental disabilities, and without disabilities using the revised Paediatric Evaluation of Disability Inventory (PEDI) Item Banks. *Am J Occupational Therapy*. 2012; 66(5): 607 – 616). As recognised by the Productivity Commission in its NDIS Costs Position Paper 2017, the current application of these tools by the NDIA in its functional and support needs assessment may be skewing the NDIA's data and wrongly suggesting that 40% of children entering the scheme do not have substantial functional deficits relative to their peers.

If PEDI-CAT continues to be a recommended functional assessment tool, in order to mitigate against the tool's flaws in making a functional assessment in young autistic children, research suggests that the PEDI-CAT, modified for autism spectrum disorder 'PEDI-CAT (ASD)', is likely to be a more efficient and sound assessment tool for this group (ibid). The PEDI-CAT (ASD) is yet to be validated, however, particularly in the Australian population. We therefore urge you to highlight that no single functional assessment tool is currently capable of capturing the range of difficulties that young autistic children can present with now, or in the future, and thus caution should be taken with use of any assessment tool to measure support needs.

The mandatory use and identification of a functional assessment tool in the [draft ASD Functional and Support Needs Assessment template](#) (pg.5) should also be reviewed. If the requirement to use and identify a specific tool remains, we would urge the inclusion in the template of a further comments or considerations sections to capture any functional or support needs the identified tool may have missed, misrepresented or inadequately prioritised.

Accessibility and reliability

The sustainability, feasibility and reliability of the approach outlined under the draft guideline to functional and needs assessments, and indeed meeting support needs under the NDIS, will be reliant on ALL consumers being able to access a functional and support needs assessment. To ensure reliable functional and support needs assessments are available to the NDIS, it should fully fund the costs of these assessments. As discussed above, the government should conduct a cost-benefit analysis of Medicare funding all or a more significant proportion of diagnosis costs.

Recommendation:

- If PEDI-CAT is to be highlighted as a preferred assessment tool, the guideline should instead encourage the use of the PEDI-CAT (ASD) to measure the adaptive behaviours and functional needs of all young children, particularly those aged 0-7.
- Functional and support needs assessments should be funded by the NDIS.

Sharing ASD Assessment findings

Amaze welcomes the direction contained in this chapter of how ASD assessment findings should be shared with consumers and others. This will ensure that consumers and where relevant, their families and caregivers are consistently provided with a detailed/transparent assessment and that assessment is delivered in a timely manner and an appropriate, sensitive, understandable and meaningful way for consumers.

To ensure that assessments are being shared in accordance with the draft guideline, ongoing funding to survey the experiences of consumers and their families/carers will be essential.

Important considerations

Amaze supports the identification of 'Important Considerations' in Chapter 12 of the draft guideline, with respect to age, gender, gender diversity, intellectual disability, CALD communities, regional or remote locations and co-occurring conditions. To date, adults, women, trans or gender diverse people, CALD communities and people in remote locations have historically been underrepresented in the data of ASD diagnosis and often their differing support needs (particularly based on gender and age) have not been met. There have also been significant misunderstandings/lack of knowledge among health professionals about when/how intellectual disability and/or mental health conditions may be differentiated or co-occur/overlap with ASD.

However, we are concerned that the overview of each Important Consideration provided in Chapter 12 will not be adequate of itself to inform professionals involved in diagnostic evaluations or FSNAs of these issues. Specific training and expertise in each of these areas should be required, and be a pre-requisite to all prescribed professions undertaking ASD diagnosis and FSNAs. This will be key to reliable diagnostic evaluations and FSNAs that consumers, their families/carers and the NDIA can have confidence in.

Autistic women.

As discussed above, we are particularly concerned that the discussion and recommendation on gender may not be adequate to capture the different needs of females in diagnostic evaluation and functional and support needs assessment.

Historically, there has been a systemic failure to identify and diagnose autistic females, predominantly due to a prevailing lack of knowledge across sectors of the differences in how ASD presents in females compared to males, as well as historic gender biases in ASD screening and diagnostic tools. Due to these failures, many autistic females are not receiving the supports and services they need throughout their lifetime and are at increased risk of misdiagnosis, abuse, financial hardship and social isolation.

The draft guideline should aim to rectify these failures and ensure that all professionals involved in the diagnostic, and functional needs assessments understand the differing presentation of autism in autistic females, and the limitations of screening and assessment tools for autistic females.

The guideline should include more detail from Evidence Table 66 about the different presentation of autism in females compared to males. It is recognised in Evidence Table 66 that females tend to have: fewer restrictive and repetitive behaviours; lower parent rating of social skills (this may reflect higher social expectations for girls); less inappropriate special interests (horses, dolls or pop stars) and play topics therefore seeming less impaired; higher incidence of disordered eating; less aggressive/hyperactive behaviours; and masking of impairment through imitation. It also recognises that females tend to have better: imaginative play; attention; concentration; coping; adaptation; compensation skills; play skills; theory of mind; language/communication; executive function; females may show more of a desire to have friends and fit in with their peer group than males, and may mask social play deficits by imitating their typically developing peers; and females who have difficulty maintaining eye contact and seem to be socially withdrawn may be thought to be 'shy' rather than having a symptom of autism. At the very least, these characteristics of autistic females should be highlighted in the guideline itself. As discussed above, the tendency of women to mask their autism characteristics during ASD assessments, as well as day to day life, must be highlighted throughout the draft guideline.

The draft guideline should also highlight the importance of gender being taken into account when assessing functional and support needs. For example, the barriers to, and development of, communication and social skills in autistic females can be very different to that of autistic males, with significant implications for the subsequent design and implementation of intervention programs (see Autism Program at Yale, 'Initiative for Girls and Women with Autism Spectrum Disorder. Yale School of Medicine, available at https://medicine.yale.edu/childstudy/autism/clinical_services/initiative/).

Co-occurring conditions

We welcome the guidance on co-occurring conditions and the recommendation that Diagnosticians must be highly familiar with the full range of conditions that commonly co-occur with ASD. However, as discussed above, we are concerned that the allied health professions identified as eligible to perform the role of a Diagnostician may not have adequate knowledge of these co-occurring conditions.

Indeed for all professions eligible to be Diagnosticians, this recommendation would need to be supported with professional training as there is currently a general lack of knowledge among these professionals regarding ASD and these co-occurring conditions, particularly commonly occurring mental health conditions (see for example, recommendation of the Victorian Parliament in its Final Report to its Inquiry into services for people with ASD, recommendation 8.4). While some resources are available online to help assist mental health and mainstream healthcare professionals working with autistic people, they can be difficult to find and quality assess, and/or are not widely publicised or targeted across mainstream health and healthcare professionals.

Further, it should also be highlighted in the guideline that not all autistic people will recognise that they are experiencing a mental health condition or feel comfortable disclosing their mental health condition to healthcare or other professionals (see Crane L et al 2017. Know your normal – Mental health in young autistic adults. Ambitious about Autism and Centre for Research in Autism and Education, UCL Institute of Education, UK, June 2017. Available at <https://www.ambitiousaboutautism.org.uk/the-research>)

Historically there has been a lack of coordination and collaboration across the disability, mainstream health and other sectors. We therefore welcome the recommendation that if a particular Diagnostician does not have the clinical qualifications or expertise to adequately evaluate a potential cooccurring condition for a given individual, then that individual should be referred to a professional who does have the expertise. However, for this to be sustainable it will need to be accompanied by better integration of government services for people with ASD and co-occurring conditions to ensure they have the capacity required to support autistic people (see for example, recommendation by the Victorian Parliament in its Inquiry into services for people with ASD – Final Report, see recommendations 8.5 and 2.2). A co-ordinated approach to training and professional development of mainstream healthcare providers (in the relationship between ASD and co-occurring conditions such as mental health) will also be required if the holistic needs of autistic people are to be met in a meaningful way.

Recommendations:

- The guideline should outline a prescribed level of training in the identified 'Important Considerations' as a prerequisite for all professionals to diagnose ASD and conduct FSNAs.
- The different presentation of ASD in autistic women compared to autistic men, as identified in Evidence Table 66, should be highlighted in the guideline itself.

- The guideline should highlight the importance of all professionals involved in an ASD assessment considering whether the consumer may be masking their autistic characteristics during ASD assessments and/or in their daily life.
- The guideline should recommend that all professionals take gender into account when assessing ASD characteristics and functional and support needs.
- The guideline should highlight that not all autistic people will recognise that they are experiencing a mental health condition or feel comfortable disclosing their mental health condition to diagnosticians.