Submission to the Select Committee on Autism

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The Australian Psychological Society Limited

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Acknowledgment
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About the APS

The Australian Psychological Society (APS) is the premier professional association for psychologists in Australia, representing more than 25,000 members. Psychology is a discipline that systematically addresses the many facets of human experience and functioning at individual, family and societal levels. Psychology covers many highly specialised areas, but all psychologists share foundational training in human development and the constructs of healthy functioning.

Psychologists are able to assist not only those who have mental health problems, but children and young people who may have an autism spectrum disorder or other neurodevelopmental disorder. Psychologists can help establish a diagnosis and can provide therapeutic input to support a person's social, relational, emotional, work and academic development across the life course.

Psychologists and autism

Psychologists are uniquely positioned to support people on the spectrum because of the nature of their training and skills, not only in assessment and diagnosis but also in the provision of evidence-based therapeutic interventions and supports.

Autism spectrum disorder (ASD) is a neurological and developmental disorder. It is known as a "spectrum" disorder because of the wide variation in types and severity of symptoms that people experience. People on the spectrum can range from very low functioning to very high functioning. It often goes undiagnosed during school years, particularly with those who display high achievement. Externally they can appear to be successful but internally often struggle with emotions, relating to others and can suffer exclusion, lack of belonging and loneliness. People on the spectrum experience high rates of comorbidity with mental health disorders, intellectual disability, other neurodevelopment disorders and medical conditions. Consequently, each person with autism presents with specific needs. This poses many challenges for the professionals and systems set up to support them.

Government support for people on the spectrum

The APS acknowledges the funding provided by the Australian Government to support people with disability, including autism[1]. However, support specific to autism in the Health portfolio is focused almost exclusively on children and the lack of support for adolescents and adults on the spectrum is glaring. The evidence supports the importance of early intervention in facilitating development and improving quality of life for people on the spectrum[2, 3] as well as reducing the social and financial burden on families and society.[4, 5]

The APS strongly supports measures to facilitate early detection, diagnosis and treatment. However, autism is a lifelong disorder and supports are needed across the life span. With appropriate interventions and supports many people with autism can live relatively independent and productive lives. There are also people who are not diagnosed during childhood but later in life when looking for help with mental health (eg anxiety & depression), social, relational and employment difficulties and whose needs may vary significantly from the support provided to those diagnosed in childhood.

Medicare arrangements

The APS has particular concerns regarding the Medicare arrangements for autism, in terms of the specific item requirements, the associated rebates and the scope of the items.

Item requirements

The current items are for assessment, diagnosis and creation of a treatment and management plan for children under the age of 13 years and interventions for children up to the age of 15. The items require referral from a medical practitioner to a consultant paediatrician or psychiatrist and allow referral to allied health practitioners for assessment services (maximum of four) and treatment services (maximum of 20 in total per lifetime).

Autism is a highly complex disorder with wide variations in presentation. Diagnosis is not straightforward and it benefits from the involvement of professionals from multiple disciplines (e.g., paediatrician, child psychiatrist, psychologist, speech pathologist, occupational therapist, and audiologist) across multiple settings (e.g., home, childcare, school, work).

The APS supports collaboration of relevant professions in the assessment, diagnosis and preparation of treatment plans for people on the spectrum. However, the requirements in their current form are unnecessarily restrictive and prevent timely engagement of clients with relevant health care professionals.

The requirement for referral first from a medical practitioner to a consultant paediatrician and psychiatrist, and then to a psychologist or other allied health for assessment, results in long delays and high costs for clients. It is reported that delays of up to two years are not uncommon for clients relying on taxpayer funded services. APS members have reported that many clients pay privately because of the time it takes to get a referral to a psychologist under the current Medicare arrangements, thereby incurring significant costs.

Schedule fees and rebates

APS members advise that current Medicare schedule fees fall well short of covering the actual cost of service provision, making it unviable for practitioners to provide these services without charging significant co-payments to clients. The typical cost of an ASD assessment is estimated to be in the order of $1,500 to $2,000, depending upon the complexity of the person's neurodevelopmental disabilities and co-occurring conditions (e.g., behavioural issues/disorders, obsessive compulsive disorder, depression, anxiety, eating disorders). The current Medicare schedule fee for a psychology assessment is $101.35 (with rebate to the patient of $86.15), meaning that psychologists are not remunerated for the cost of service provision without charging significant co-payments to their clients (children) and full payment by adolescents and adults. Inadequate remuneration is a significant disincentive to psychologists providing their services under Medicare, although some psychologists accept a loss of income to not disadvantage vulnerable clients. This is a practice that is clearly unsustainable.

Economic analysis conducted by Synergies[4,5] has shown that early assessment and intervention among children can reduce the average cost burden to the Government and community by between $0.75

million and $1.3 million per child. While there is less known about the cost benefits to enabling appropriate assessment and diagnosis among adolescents and adults, it is clear there is substantial cost savings to Government associated with appropriately funding assessment and diagnostic services and therapy within the Medicare Benefits Schedule (MBS).

Scope of services

The APS holds the strong position that developmental neurocognitive assessments should be funded under Medicare. Such assessments are essential to enable interventions to be appropriately designed and tailored, as they delineate the impact of cognitive, behavioural and psychosocial issues that are associated with developmental disorders, including autism. Where the complexity of the presentation requires expert opinion, these assessments should be provided by psychologists with Area of Practice endorsement in Clinical Neuropsychology or Educational and Developmental Psychology.

While some assessments for children can be undertaken under the Medicare arrangements, these are limited to diagnostic assessments (that is, those that are used to contribute to a diagnosis of autism). APS members report that the item descriptors allow insufficient time to conduct thorough diagnostic assessments. Further, other assessments of cognitive and adaptive behaviour, together with assessment(s) of challenging behaviours are required to effectively tailor supports to an individual's needs. These assessments are not currently funded under Medicare. Report writing, which is time consuming and essential to enable client access to NDIS and other disability supports, is also not covered.

The current arrangements act as a substantial barrier to detection and intervention to support people with autism. According to the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*[7] (National Guideline), endorsed by the National Health and Medical Research Council (NHMRC), key to reducing the burden of autism is access to appropriate and tailored interventions that can only be ascertained once a thorough assessment has been conducted. The current parameters of the MBS *Helping Children with Autism* program do not support the provision of best practice diagnosis, assessment and care to individuals with autism.

Medicare Recommendations

The APS recommends that the current autism items be reviewed, with a particular focus on:

- enabling greater flexibility in referral requirements, including direct referral from a GP to a psychologist to reduce waiting times and costs to clients
- removing age limits on access to the items and the number of services that can be provided across the lifespan
- amending schedule fees and item descriptors to better reflect the actual time, scope, and costs of service provision by psychologists with appropriate training and expertise, noting that this will vary with age
- expansion of the items to include neurocognitive assessments conducted by appropriately trained psychologists

Investments in training and education

The complexity of autism presentations means that it is not uncommon for unskilled practitioners to miss or misinterpret the signs of autism in their clients, and for there to be diagnostic 'over-shadowing'[a] and mis-diagnosis. Where this occurs, interventions and supports may be inappropriate and ineffective.

The APS considers there is a critical need to upskill practitioners (both medical and allied health) in the nature of autism presentations across the lifespan, from infancy to adulthood, so that they can more readily identify individuals who should be referred for assessment and appropriate support.

Members have indicated that clients experience many difficulties navigating service provision, follow-up support and obtaining referrals. Providing training and resources to health professionals will assist them to better support their clients in accessing services and in advocacy and decision-making.

Members have also expressed concern about exposure of people on the spectrum to non-evidence based and harmful treatments (e.g., facilitated communication, chelation therapy, bleach therapy, stem cell therapy).[8] There is a need to address mis-information about treatments to safeguard against harm. This is particularly important in an environment of assessment and treatment delays and high costs, where alternative therapies may be sought because they may appear more accessible, more readily available or less expensive.

The APS strongly recommends that the use of evidence-based therapies is embedded in all programs relating to the treatment and support of people on the autism spectrum, such that only approved and evidence-based interventions that are specified in program guidelines are funded.

Training and Educations Recommendations

The APS recommends that funding be provided to:

- support education and training of health practitioners across disciplines to improve identification of individuals requiring further specialised assessment across the lifespan
- upskill practitioners providing services to people on the spectrum to ensure that best-practice interventions are understood and applied
- provide resources to educate and support families and caregivers to make safe and informed decisions regarding care.

[a] Diagnostic over-shadowing occurs when a practitioner assumes that certain symptoms, behaviours or characteristics are related to a particular condition or diagnosis, rather than fully exploring cause of symptoms.

Issues of gender, sexuality and mental health

The APS notes the Committee's interest in gender bias in autism diagnosis and assessment and agrees that there is some evidence to suggest that females may be less likely to be diagnosed with autism than males.[9, 10]

There is evidence of an under recognition of autism among females due to a bias towards males in the diagnostic process (tools used and practitioner bias) and emerging evidence that females may be better able to 'camouflage' (compensate for or mask characteristics of autism) their communication and social difficulties.[11]

There is also emerging evidence of gender differences in the presentation of autism and in mental health disorders experienced by people on the spectrum. For example, it has been reported that approximately 30% of females on the spectrum received a diagnosis of an eating disorder before their diagnosis of ASD.[12] Depression and anxiety disorders are also very high in females on the spectrum, while young men on the spectrum are at higher risk of suicide.[13]

Further, clinical practice indicates heightened levels of gender discomfort and an overrepresentation of gender dysphoria within people on the spectrum. Research within LGBTQI+ communities has found that when compared to typically developing individuals, those on the spectrum reported a higher number of gender-dysphoric traits.[14]

Autism, mental health, and gender and sexual identity intersect, which can amplify issues for the people affected.[15] People on the spectrum who also identify as LGBTQI+ are more likely to experience serious mental health issues than those from heteronormative populations.[15]

These relationships and interactions are complex and not well understood. They have potentially devastating consequences for the people involved. Further research is required to enable appropriate supports to be made available to this particularly vulnerable group.

Research

The APS notes the funding provided for autism research through the Autism CRC and the National Health and Medical Research Council (NHMRC) over the past 10 years. However, there are gaps in the research and a need to build on existing research to further enhance understanding of this complex disorder.

Research Recommendations

The APS recommends continued investment in autism research, giving priority to:

- issues of mental health broadly, and including the intersections between gender and sexuality
- applied psychological supports and interventions across the lifespan for people with ASD

- improving screening and diagnostic tools, including as they relate to the identification of females on the spectrum
- the presentation and treatment of people on the spectrum from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds.

To ensure best use of research funding and support the development of the evidence base, it is essential that there is transparency and accountability in funding processes and access to research findings.

National Disability Insurance Scheme (NDIS)

The APS contends that there are significant deficiencies in the NDIS arrangements, including as they relate to people on the autism spectrum. These deficiencies have been articulated in various APS submissions to inquiries into the operation of the NDIS and the Committee is referred to those (see Appendix).

As stated in its previous submissions, the APS considers that the NDIS does not effectively and unambiguously define and/or appropriately translate which conditions, including ASD, are within the Scheme's scope. This leads to significant problems for those attempting to apply for NDIS and for those who provide care.

The APS is particularly concerned by the feedback from some members that NDIS planners are instructing participants and their carers that the NDIS will not approve psychological interventions for ASD and that they are to seek treatment under the Medicare Better Access to Mental Health Scheme (Better Access). Interventions for ASD are fundable under specific Medicare items (for children), but as indicated above, they are limited in nature.

This attempt to drive participants from the NDIS to Medicare has been particularly common in relation to autism, although interventions for it, as previously observed, are limited under Medicare. This is prominent in relation to Early Childhood Support (ECS) for autism, but approval and funding support for interventions in relation to adults with ASD are also deficient in scope.

Individuals with ASD are diagnosed in one of three "Levels" of support: with ASD Level 1 equating to a mild presentation of autism and ASD Level 3 equating to a severe presentation. There are many individuals with ASD Level 1 in the Australian community. They are currently excluded from the NDIS and receive no support under the Scheme, except for Information, Linkages and Capacity Building (ILC) supports. For example, NDIS participants assessed as ASD Level 1 and without a comorbid intellectual disability are commonly excluded and subsequently left with minimal community supports.

There is an urgent need to resolve the current lack of clarity regarding how to distinguish a person who should be treated under the NDIS from those whose care should be funded under the MBS. For this purpose, the APS recommends that the NDIS and the National Disability Insurance Agency (NDIA) engage with the APS to amend the guidelines for plan development for participants with ASD and decision-making processes of planners, local area coordinators and support coordinators.

The APS is also concerned with the NDIS requirements regarding assessment and diagnosis for ASD. The operational guidelines specify that only psychologists with Area of Practice Endorsements in Clinical Psychology can contribute to the assessment and diagnosis of autism and exclude those with endorsement in Clinical Neuropsychology and Educational and Developmental Psychology.

The National Guideline specifies that some assessments (such as Single Clinician Diagnostic Evaluations) require Area of Practice endorsement in Clinical Psychology, Clinical Neuropsychology, and Educational and Developmental Psychology. It also articulates other involvement in assessment and diagnostic processes (such as functional assessments) that can be undertaken by any registered psychologist with the requisite skills and experience. The exclusions in the NDIS arrangements are not consistent with the National Guideline, not evidence-based and not in the interests of the NDIS or its participants. The APS considers that an urgent review of the requirements relating to ASD in the NDIS is warranted.

NDIS Recommendations

The APS recommends:

- that the NDIS and the National Disability Insurance Agency (NDIA) engage with the APS to amend its guidelines and requirements to ensure appropriate engagement of psychologists and informed decision-making by NDIS staff in relation to psychological supports
- that the Committee recommends that NDIS ensures its practices and requirements align with best practice, as set out in the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*.

References

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APS Activities related to Autism

1. Ethical guidelines for psychological practice with clients with an intellectual disability
2. Practice guide for psychological testing with people with disability, 2018
3. The APS Psychology of Intellectual Disability and Autism Interest Group provides resources and professional development activities to support members working with this client group
4. Practice Guide: Alternatives to restrictive practices in intellectual and developmental disability, 2018
5. Online Learning about Autism Spectrum Disorder – 10 hour course, developed in 2020
6. Autism spectrum disorder (ASD) practice guide
7. Autism Spectrum Disorder - Public information webpage
8. Selected Submissions:
    - APS submission to the Autism CRC (The Cooperative Research Centre for Living with Autism) on the draft National Guideline: *The diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder (ASD) in Australia.* 2017.
    - APS submission to MBS Services for Children with Autism Spectrum Disorder, 2018.

Appendix: APS submissions relating to the NDIS

- Joint Standing Committee on the National Disability Insurance Scheme: NDIS Workforce - 2020
- NSW Parliament Legislative Council Portfolio Committee No. 2 - Health and Community Services inquiry into Implementation of the NDIS – 2018
- Joint Standing Committee on the National Disability Insurance Scheme (NDIS) inquiry into market readiness for the NDIS - 2018
- Joint Standing Committee on the National Disability Insurance Scheme (NDIS) inquiry into transitional arrangements for the NDIS – 2017
- Joint Standing Committee on the National Disability Insurance Scheme inquiry into the Provision of services under the NDIS Early Childhood Early Intervention Approach - 2017
- Productivity Commission position paper on its study into NDIS costs - 2017
- National Disability Insurance Scheme (NDIS) Costs: Productivity Commission Issues Paper February 2017 - 2017
- Provision of services for people with psychosocial disabilities related to mental health conditions under the National Disability Insurance Scheme (NDIS) – 2016
- Joint Standing Committee on the National Disability Insurance Scheme Inquiry into accommodation for people with disabilities and the NDIS - 2016