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RACP Submission to the Senate Select Committee on Autism

May 2020

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 18,000 physicians and 8,500 trainee physicians, across Australia and New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

Credit: Healing Place, by Riki Salam

The RACP acknowledges the Traditional Owners of this land – their ancestors and elders – and is committed to reconciliation with Indigenous Australians.

For more information on the RACP's reconciliation actions, go to the RACP's Reflect Reconciliation Action Plan

Executive Summary and Recommendations

The RACP welcomes the opportunity to provide a submission to the Select Committee on Autism (the Select Committee).

Autism Spectrum Disorder (ASD) is the collective term for a group of neurodevelopmental disorders characterised by persistent deficits in social communication and social interaction, and by repetitive patterns of behaviour and restricted interests. The behavioural features that characterise ASD are often present before three years of age but may not become apparent until the school years or later in life. The developmental challenges, signs and/or symptoms can vary widely in nature and severity between individuals, and in the same individual over time, and may be accompanied by mental and physical health problems.

The RACP welcomes the decision of the Select Committee to initiate further improvement of services for individuals diagnosed with ASD, and their families, in Australia. While recognising the contribution to ASD diagnosis and treatment of practitioners from a range of professions, the RACP believes that physicians and psychologists with relevant training and experience are best placed to play a lead role in the co-ordinating and integration of services. The RACP supports continued investment in clinically relevant research, as a means of maintaining service quality and effectiveness.

The RACP emphasises and celebrates diversity and inclusiveness in relation to support for individuals and families living with the challenges of an ASD diagnosis. Although people living with ASD will share many of the same characteristics, each and every person living with ASD is different. Some will go through life with very little support, while others will need a lifetime of care and support. ASD should not be seen only through the lens of the NDIS.

ASD is a life-long condition and people with ASD need other types of supports that may not be provided through the NDIS, such as education, employment and social inclusion. This needs a broader approach to ASD that is not only focused on support, but on making schools, workplaces and so on adaptable to people with ASD. This may require changing our approach to classroom learning and other norms in our society. Irrespective of the outcome of an ASD diagnosis the goal is to provide assistance to the person and their family in relation to their concerns.

The RACP is committed to supporting enhanced services, support and life outcomes for children, adolescents and adults with ASD. As an organisation that draws on the professional experience of physicians in a range of specialities, the RACP has concerns around existing levels of support and healthcare for people living with ASD across all ages and social groups in Australia.

This submission focuses on the specific terms of reference (ToR) that are relevant to the work of RACP Fellows.

The recommendations outlined below are based on consultation with RACP Fellows with specific expertise in ASD, analysis of existing RACP policies in this area and consideration of national and international guidelines for best practise. The RACP calls on the Commonwealth Government to:

1. Ensure that ASD assessments are:
    - Conducted by a multidisciplinary team of experienced health professionals, but that key elements of establishing an ASD diagnosis are only be delivered by a suitably experienced or trained clinician such as a paediatrician, psychologist, psychiatrist or neurologist.
    - Focused on developmental and functional skills and ensures that appropriate support and intervention are provided to the person, and their family, irrespective of the specific diagnosis.
2. Review Medicare Benefits Schedule (MBS) item numbers that relate to ASD MBS with the view to:
    - Introducing an annual MBS item number that would allow an hour-long review of patient goals and needs,
    - Introducing a stand-alone item number for transition to adult services,

    - Allowing item numbers that exist for people with intellectual disability to be extended to adults with ASD.

3. Ensure culturally appropriate services are available which are community informed and Aboriginal controlled where possible to assist the provision of services to Aboriginal and Torres Strait Islander people with ASD. The RACP also recommends that increased assistance is given to the families of Aboriginal and Torres Strait Islander children with ASD to access the NDIS and post-diagnostic support services.
4. Develop a robust, fully funded strategy for implementation of The National Guideline for the Assessment and Diagnosis of ASD and establish a clinical reference group to support this implementation including experienced clinicians who diagnose ASD in children and adults.
5. Invest in the development and trial of integrated, interagency models of care and a needs-based support system that cater to individuals living with ASD according to their required level of support and expertise needed.
6. Improve facilitated access to mental health provision that is appropriate to the needs of individuals diagnosed with ASD (for example, Child Youth Mental Health Service (CYMHS) or Headspace) and provide specialist training/supervision for mental health staff in the unique needs of people with ASD.
7. Improve the quality and accessibility of health services for people with ASD to ensure a positive transition to adult health services.
8. Implement the recommendations in the Tune Review and ensure that NDIS planners and service providers are supported to develop expertise to provide support for NDIS participants with ASD.
9. Improve the accessibility and adequacy of information provided by Early Childhood Early Intervention (ECEI) pathway and ensure that ECEI interventions are delivered in a timely and person-centred manner.
10. Fund community-based research into the identification and diagnosis of ASD in Aboriginal and Torres Strait Islander families and how to better support their needs and aspirations.
11. Work with academic institutions and organisations such as the National Health and Medical Research Council (NHMRC) to identify and assess emerging evidence of promising therapeutic interventions for people with ASD.
12. Develop a 5-year National Autism Strategy, as part of a broader strategy for adults and children with neurodevelopmental and behavioural conditions, with measurable targets and outcomes, in partnership with people living with ASD, their families/carers and health professionals.

Response to specific Terms of Reference

The prevalence of ASD in Australia (ToR B)

ASD is now one of the most common diagnoses made by Australian paediatricians.[1] In 2015, it was predicted that 83 per cent of Australians with ASD were aged under 25.[2] The number of people with ASD in Australia has increased considerably in recent years. In 2018 Australia's largest ASD-specific service provider, Autism Spectrum Australia (Aspect) estimated that 1 in 70 people in Australia have ASD, a 40% increase from the previous estimate in 2014 of 1 in 100.[3] It is thought that the apparent increase in prevalence is predominantly due to an increased awareness of ASD in the community and improvements in recognising and diagnosing ASD in people of all ages.

Current approaches and barriers to consistent, timely and best practice ASD diagnosis (ToR A)

Though some aspects of ASD are well understood, the causes, development over time, variation in presentation from one person to another, gender diversity and effective intervention and treatment are yet to be clarified. It is likely that ASD is the developmental endpoint of a number of neuro-developmental pathways, rather than comprising a single condition. Adding to the complexity of diagnosis and intervention is the common co-occurrence of features such as intellectual disability, which may have more impact on development and achievements than ASD itself.

Children with ASD and their families benefit from early intervention and developmental supports in the early years and families often need support in making decisions about therapies, interventions and supports to improve outcomes and opportunities. However, the trajectories of developmental disorders in the very early childhood years can be difficult to accurately predict. Children have a wide variety of abilities, ways of thinking and behaviours all of which change over time, making diagnosis of specific neurodevelopmental and behavioural (NDB) disorders very complex. Children who are medically unwell, sleep deprived, bullied or distressed can sometimes display similar behaviours to those with NDB disorders.

This task of providing accurate ASD diagnoses in Australia is further complicated by significant variability between States and Territories in the composition of the clinical diagnostic team. While some states require an ASD diagnosis to be made through consensus of an experienced multidisciplinary assessment team of a paediatrician/psychiatrist, psychologist and speech pathologist, other states have less stringent criteria.[4]

The RACP recognises the importance of multidisciplinary teams that include speech pathologists, occupational therapists and educational psychologists among others, in the diagnosis of ASD. However, accurate diagnosis involves integration of clinical signs and symptoms, careful consideration of alternative possible diagnoses and detection of important contributing health conditions, which require specialist clinical skills.

While the RACP understands the importance and utility of diagnosis in some situations it is important to recognise that in some situations a diagnosis is not helpful. A number of NDB conditions incorporate the concept of a 'spectrum' of disorder. A child at one end of the spectrum may only need minimal supports to reach their potential while another child, with the same condition, may have complex problems that require lifelong care. The nature of the intervention best suited for the child's needs are not consistently informed by diagnosis alone, but by a range of factors including family and cultural issues, general development and additional health concerns. These factors have resulted in a rigid categorical approach to diagnosis of ASD

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[1] Hiscock, H., Danchin, M. H., Efron, D., Gulenc, A., Hearps, S., Freed, G. L. & Wake, M. (2017). Trends in paediatric practice in Australia: 2008 and 2013 national audits from the Australian Paediatric Research Network. Journal of paediatrics and child health,

[2] Autism in Australia, Australian Institute of Health and Welfare [Internet]. Australian Institute of Health and Welfare. 2020 [cited 1 June 2020]. Available from: https://www.aihw.gov.au/reports/disability/autism-in-australia/related-material

[3] Autism prevalence rate up by an estimated 40% to 1 in 70 people [Internet]. Autism Spectrum Australia (Aspect). 2020 [cited 1 June 2020]. Available from: https://www.autismspectrum.org.au/news/autism-prevalence-rate-up-by-an-estimated-40-to-1-in-70-people-11-07-2018

[4] Taylor, L., Brown, P., Eapen, V., Harris, A., Maybery, M., Midford, S., Whitehouse, A. (2016). ASD spectrum disorder diagnosis in Australia: Are we meeting best practice standards? ASD CRC: Brisbane

being less than helpful in some cases, and a growing preference towards a more extensive diagnostic formulation that adopts a comprehensive bio-psycho-social perspective.

While the diagnosis of ASD can provide useful information about the types of interventions and likely causes of difficulties that may be helpful for the person, a precise categorical diagnostic approach for ASD may not be feasible or necessary for a particular individual. In addition, some individuals, families and cultural groups may regard diagnosis as stigmatising. Comprehensive assessment and individual case formulation makes it possible to identify patient needs in the absence of categorical diagnosis. It also facilitates adjustment of the formulation in the light of changed circumstances, and at key points in the patient journey such as transition from child to adult services.

Recommendation 1: The RACP strongly supports a multi-disciplinary approach to diagnostic formulation that focuses on developmental and functional skills and ensures that appropriate support and intervention are provided to the person, and their family, irrespective of the specific diagnosis The RACP recommends that key elements of establishing an ASD diagnosis should only be delivered by a suitably experienced or trained clinician such as a paediatrician, psychologist, psychiatrist or neurologist.

Recommendation 2: The complex, multidisciplinary nature of ASD diagnosis needs to be reflected in the Medicare reimbursement system. Paediatricians have a single MBS item number under Medicare (135) when ASD is either diagnosed or they would like to direct funding to an allied health specialist to help with the diagnosis. The RACP recommendations reviewing the Medicare Benefits Schedule (MBS) item numbers that relate to ASD MBS with the view to:

- Introducing an annual MBS item number that would allow an hour-long review of patient goals and needs,
- Introducing a stand-alone item number for transition to adult services,
- Allowing item numbers that exist for people with intellectual disability (701, 703, 705, 707) to be extended to adults with ASD.

Although ASD is as prevalent in Aboriginal communities as non-Aboriginal communities, there are fewer ASD services and supports available to families in Aboriginal and Torres Strait Islander communities, particularly services and supports which recognise the distinctive culture of Aboriginal and Torres Strait Islander people. Aboriginal and Torres Strait Islander peoples also continue to face institutional and interpersonal racism in the health system that compounds health inequities.

Embedding of culturally safe practices in clinical and health care environments across the health system is the way to address inequalities in health access and outcomes for Aboriginal and Torres Strait Islander peoples. A culturally appropriate health service is one which takes into account local language or languages, beliefs, gender and kinship systems, delivers care in a manner which respects these important factors and is free of discrimination. To address the long-term implications of institutional racism, it is important for health services to undertake an honest evaluation of cultural safety and the competency of its health care professionals.[5]

The need for these particular, tailored, services was demonstrated in a recent report by Lilley, Sedgwick and Pellicano from Macquarie University[6] which described the experiences of Aboriginal and Torres Strait Islander families of caring for a child with ASD. This report showed that families often receive little or confusing advice about post-diagnostic support, and experience long waiting lists for early intervention, high cost and limited availability of therapies, particularly in regional and remote Australia.

They also identified that another barrier to access services is the lack of trust in government, the legacy of the Stolen Generations and the large, and growing, numbers of Aboriginal and Torres Strait Islander children

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[5] RACP Medical Specialist Access Framework, https://www.racp.edu.au/advocacy/policy-and-advocacy-priorities/medical-specialist-access-framework

[6] Lilley R, Sedgwick M, Pellicano E. WE LOOK AFTER OUR OWN MOB: Aboriginal and Torres Strait Islander Experiences of Autism [Internet]. Macquarie University; 2020. Available from: https://www.mq.edu.au/about/about-the-university/faculties-and-departments/faculty-of-human-sciences/departments-and-centres/department-of-educational-studies/news-and-events/news/news/first-report-into-autism-in-aboriginal-and-torres-strait-islanders-released,-revealing-shortage-of-supports-and-services/FINAL-REPORT-We-Look-After-Our-Mob_SCREEN.pdf

placed in out-of-home care. The experiences of racism in mainstream services can make people extremely wary of seeking help from such services. Poverty and marginalisation can also impede access to services: even for free services, difficulties getting to such services can be a disincentive and insufficient or confusing post-diagnostic advice and support. The report demonstrated supports tapering off altogether as children grew older.

Recommendation 3: Ensure that culturally safe and appropriate services are available which are community led and controlled where possible to assist the provision of services to Aboriginal and Torres Strait Islander people with ASD. The RACP recommends that increased assistance is given to the families of Aboriginal and Torres Strait Islander children with ASD to access the NDIS and post-diagnostic support services, and information is designed specifically for Aboriginal and Torres Strait Islander communities, in varied formats and translated into local languages.

The National Guideline for ASD Diagnosis

The Autism CRC collaborated with the National Disability Insurance Agency (NDIA) to develop The National Guideline for the Assessment and Diagnosis of ASD Spectrum Disorders in Australia (the Guideline), which was released on 16 October 2018. The RACP was consulted [7] on the draft Guideline and was represented on the Steering Committee which oversaw its development.

Despite these national guidelines, many people with ASD in Australia are not receiving the level of support recommended in the Guidelines. A robust, fully funded strategy for implementation of the Guidelines would ensure that all Australians can receive the best evidenced diagnostic practices, regardless of their age or location, and make informed decisions about next steps.

Recommendation 4: The RACP recommends the development of a strategy for implementation of the Guidelines. The RACP wrote to the Minister for Social Services in December 2018 to recommend the establishment of a clinical reference group including neurodevelopmental and behavioural paediatric expertise to guide implementation of the Guideline. This clinical working group would ensure the guideline is adopted and implemented by clinicians and services across Australia who are involved in ASD assessment and diagnosis. The Neurodevelopmental and Behavioural Paediatric Society of Australasia (NBPSA) has already agreed to support the establishment of an expert reference group to advise on implementation of this new Guideline.

The interaction between services provided by the Commonwealth, state and local governments (ToR F)

Integrated, multidisciplinary models of care

Support for children and adults with ASD sits across a broad range of sectors including health, education, disability, and parent/consumer sectors. It is important that each sector is recognised for their unique contributions, but also that they work together to ensure the best outcomes for people with ASD and their families. The integrated approach can work especially well for individuals with ASD who often have significant comorbidity of physical disorders[8] and require more specialised assessment, care and support from multiple experts such as physicians, psychologists, speech pathologists and occupational therapists. For children, paediatricians are often the best placed specialists to coordinate this care, given their child development expertise and longer consultations available through Medicare, compared with GPs. This type of care is also important for people from vulnerable populations. Best practice care for people living with ASD is patient-centred and outcomes focused; which supports coordination across different providers and settings; and promotes new and multidisciplinary models of care.

The RACP supports the Comprehensive Health Assessment Program (CHAP),[9] developed by the Cooperative Research Centre for Living with Autism Spectrum Disorders (the Autism CRC), which is a tool designed to

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[7] RACP Submission to the diagnostic process for children, adolescents and adults referred for assessment of autism spectrum disorder in Australia: National guideline, https://www.racp.edu.au/docs/default-source/default-document-library/racp-submission-asd-draft-national-guidelines.pdf?sfvrsn=f5d9031a_4

[8] Cawthorpe D. Comprehensive Description of Comorbidity for Autism Spectrum Disorder in a General Population. The Permanente Journal. 2016

[9] Lennox, N. Comprehensive Health Assessment Program (CHAP), https://qcidd.centre.uq.edu.au/resources/chap [Accessed 26 May 2020]

prompt a comprehensive health assessment for adults with intellectual disability. CHAP has been validated through several Australian studies and its importance has been recognised by leading international researchers. Researchers at Autism CRC are currently developing and trialling an adapted CHAP program for adults and adolescents with intellectual disability who have ASD.

Recommendation 5: The RACP recommends that the Commonwealth Government invest in integrated, multidisciplinary models of care characterised by effective and sustained collaboration across practitioners and agencies in health, disability, education, and family and community services. Existing evidence-based models of multi-disciplinary care can be translated to the provision of health care for people with ASD.

Support for mental health conditions

Mental health conditions occur at a much higher rate in people with ASD[10] than the general population. The high rates of comorbidity between ASD and other psychological disorders, including depression and anxiety, indicate that standard behavioural approaches are not adequately addressing issues related to mental health in this population.[11] There is poor access to mental health services that are tailored to the needs of a person with ASD and their family.

The complex interplay between ASD and trauma is also a growing area which must be researched and recognised. Currently there is limited funding for therapy/support for children who have experienced trauma and they often are diagnosed (be this a correct or incorrect diagnosis) with ASD to secure funding for therapies.

Recommendation 6: The RACP recommends improving facilitated access to mental health provision that is appropriate to the needs of individuals diagnosed with ASD (for example, Child Youth Mental Health Service (CYMHS) or Headspace). These services must provide specialist training/supervision for mental health staff in the unique needs of people with ASD. Pathways into mental health therapies should be made available for those with adverse childhood experiences to ensure that they are not required to acquire an incorrect or unnecessary diagnosis of ASD.

The demand for and adequacy of Commonwealth, state and local government services to meet the needs of people with ASD at all life stages (ToR E)

Transitions between child and adult health services

A person’s experiences during the stage of life at which young people are transitioning to adult health services can play an important role in making the transition into adulthood both positive and successful. Adults with ASD often need ongoing support to meet increasing social demands related to independent living, forming friendships and intimate relationships, and successful employment.[12] In turn, social isolation and unemployment likely contribute to poor mental health and higher rates of suicidal ideation in this population.[13]

Paediatric and adult specialist health systems are often quite different and transitioning between the systems may create new barriers to accessing health care for young people. These may include lack of developmentally appropriate support and additional financial costs. Developmentally appropriate health services promote the transition between child and adult oriented services, encourage engagement in an appropriate level of health care (including primary health care) and reduce the risk of young people “dropping out” of health care.

Recommendation 7: The RACP strongly supports improving quality and accessibility of health services for young people with ASD transitioning to adult health services. All young people with a chronic illness or disability should have a health care provider who takes specific responsibility for their transition to adult health care. This includes the coordination of community, primary, specialty and allied health services, as well as the development of up-to-date detailed, personalised transition plans which are reviewed as the person develops

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[10] Rosen T, Mazefsky C, Vasa R, Lerner M. Co-occurring psychiatric conditions in autism spectrum disorder. International Review of Psychiatry. 2018;30(1):40-61.

[11] Fuld S. Autism Spectrum Disorder: The Impact of Stressful and Traumatic Life Events and Implications for Clinical Practice. Clinical Social Work Journal. 2018;46(3):210-219.

[12] Howlin P, Moss P. Adults with ASD spectrum disorders. Can J Psychiatr. 2012;57(5):275–83.

[13] Cassidy S, Bradley P, Robinson J, Allison C, McHugh M, Baron-Cohen S. Suicidal ideation and suicide plans or attempts in adults with asperger’s syndrome attending a specialist diagnostic clinic: a clinical cohort study. Lancet Psychiatry. 2014;1(2):142–7.

and his/her circumstances change.[14] Additional care should be taken in the transition into adult health care of vulnerable young people without family support, or in the care of the state.

ASD understanding and support within the NDIS (ToR H(i))

The NDIS can be complex and hard to navigate and access is highly variable, particularly for vulnerable groups. Participants must be sufficiently supported to engage adequately throughout the process, from access application, to goal setting, planning and the review and appeals processes. The recent review of NDIS legislation (the Tune Review) made 29 recommendations[15] to cut wait times and red tape associated with the NDIS, and simplify the application process. The RACP supports the intent of the Tune recommendations and strongly encourages the Commonwealth Government to prioritise its response to the Tune Review and to commit to improving the NDIS experience.

The September 2019 quarterly report of the NDIS from the COAG reform council shows that people who have a diagnosis of ASD currently represent 34% per cent of all participants enrolling in the NDIS.[16] Requirements for the frequency and intensity of support for people with ASD depends very much on how ASD affects the individual. Some people with ASD need intensive support to build their skills and capability in particular areas, while others do not. The support of the NDIS is critical in this respect, as it is a person-centred system where the participant's goals and needs drive the levels of support needed. Participants must be sufficiently supported to engage adequately throughout the process, from access application, to goal setting, planning and the review and appeals processes.

The experience, expertise and qualifications of NDIS staff can vary greatly. Some RACP Fellows report that the level of understanding of a client's impairments tends to vary greatly which can lead to different funding levels for similar clients, both in terms of core supports and capacity building supports. Planners have also been reported to act independently in deciding which requests will be funded and often do not necessarily accept the recommendations of experienced clinicians.

Considering the high proportion of NDIS participants who have a diagnosis of ASD, NDIS planners must develop awareness of the nuances associated with developmental disabilities, to ensure that support of people with broader neurodevelopmental challenges can be planned. This includes situations where the diagnosis is uncertain or yet to be determined, as is often the case for preschool aged children. Any assessment of ASD concerns must be undertaken within the context of a broader neurodevelopmental, behavioural and functional assessment. Aspects of neurodevelopmental and behavioural assessment will also need to be reviewed over time as children progress through various stages of development, and the nature and level of support adjusted accordingly. Practitioners must also have an awareness of the comorbid mental health disorders that commonly occur in ASD and capacity to link a client to appropriate therapy and support services to enable effective management of their mental health issues.

Recommendation 8: The RACP recommends that NDIS planners and service providers have sufficient expertise and training to understand distinct support needs of ASD patients and their families, including help around navigating the NDIS system. Care plans should be informed by guidelines or other resources such as an evidence-based framework developed by appropriate clinicians. The Government must prioritise addressing the issues raised in the Tune Review and commit to implementing the recommendations to improve the NDIS experience.

The utility of the Early Childhood Early Intervention Pathway for children with ASD (ToR H(ii, iv))

Neurodevelopmental and behavioural diagnoses often overlap and interact. An impact of this is that, for many children, an accurate diagnosis may not be clear or possible early on in life. Research suggests that it is important that complexity, including psychosocial context, is considered and that therapy is not just targeted at

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[14] Autism Europe. Persons with Autism Spectrum Disorders Identification, Understanding, Intervention [Internet]. 2019 p. 2. Available from: https://www.gautena.org/pdf/autismo/PersonasconAutismo(INGLES).pdf

[15] Tune D. REVIEW OF THE NATIONAL DISABILITY INSURANCE SCHEME ACT 2013 [Internet]. 2019. Available from: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

[16] COAG Disability Reform Council Quarterly Report 30 September 2019

ASD symptoms but at the child holistically, reinforcing the need for functional rather than single diagnosis assessments.[17]

Concerns about developmental problems in early childhood lead to times of great uncertainty for families with many signing up for as much therapy as possible, believing this is in the best interests of their child. This is leading to a proliferation of private, for-profit, fee for service therapy businesses and an erosion of the recommended key worker model of delivery, a model supported by research and the guiding principles of capacity building and supporting families to care for their child.

While the Early Childhood Early Intervention Pathway (ECEI) provides resources to support intervention for children up to seven years of age and is an important pathway for children to seek early support and begin treatment, there is a need to respect the spirit of NDIS' 'choice and control'.

Access to care can be a key challenge for families of children with ASD who may struggle to find and connect to appropriate services. A recent investigation carried out by the Australian Broadcasting Corporation (ABC)[18] revealed that waiting times for children under the age of six to access disability support under the NDIS depends on the wealth of the suburb in which the child lives, with some in poorer suburbs waiting almost 2 years for a diagnosis under the public system. This is unacceptable. To access the ECEI program, a professional must identify a developmental delay. For any long-term early intervention supports, a diagnosis like ASD must be made.

Research shows that early intervention is particularly important for children with ASD as it may lead to improvements in language abilities and overall more positive outcomes in development. [19] It is important that those children who do not have official diagnosis are able to access NDIS.

The ECEI can also be and difficult to access due to the multitude of access pathways, and the lack of information provided on how to navigate the system. For example, the NDIS webpage does not currently state clearly:

- the role of Local Area Coordinators and other key worker roles
- an explanation of the role and function of the ECEI
- what services ECEI organisations provide.

The information provided needs to be clearer, more extensive, and easier to find both on the NDIS website and through other NDIS access points (e.g. information provided to medical professionals, schools, childcare centres etc.).

Recommendation 9: The RACP recommends that the Commonwealth Government improve the accessibility and adequacy of information provided by ECEI, and ensure that ECEI interventions are delivered in a timely and person-centred manner. The Government must also ensure that the ECEI and resulting access to NDIS funding is not only accessible to those who have an official diagnosis but instead focused on the needs of the child.

The adequacy of funding for research into ASD (ToR I)

ASD is a complex disorder, for which there exist a wide range of potentially efficacious intervention strategies, which can be delivered not only by health professionals but also by practitioners in education, sport, speech and language therapy, and psychological therapies. Many valuable interventions involve active engagement of carers and family members.

The RACP has consistently advocated for diagnosis and treatment based on the best available scientific evidence, including innovative and emerging treatments. One example of a recent emerging intervention can

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[17] Sandback M et al, Project AIM: Autism Intervention Meta-Analysis for Studies of Young Children, Psychological Bulletin, American Psychological Association 2020, Vol.146, No1,1-29 5

[18] Two months instead of two years — how the rich are getting faster access to the NDIS [Internet]. Abc.net.au. 2020 [cited 1 June 2020]. Available from: https://www.abc.net.au/news/2020-02-13/childrens-access-to-disability-funding-depends-on-their-suburbs/11917466

[19] Whitehouse, A, Varcin, K, Alvares, G. Pre-emptive intervention versus treatment as usual for infants showing early behavioural risk signs of ASD spectrum disorder: a single-blind, randomised controlled trial. Lancet Child & Adolescent Health. 2019 3(9): 605-15

be found in recent studies relating to the efficacy of bumetanide on neurocognitive development of children with ASD.[20]

One specific area which warrants further investment is the current lack of research regarding the experience, from diagnosis to support, of children, young people and adults with ASD in culturally and linguistically diverse communities including Aboriginal and Torres Strait Islander communities. This absence has resulted in minimal understanding of how these communities across Australia perceive ASD, the services and supports that they are currently being offered and the services – from the early years and into adulthood – from which they might benefit the most in the future. It is critical that the voices of Aboriginal and Torres Strait Islander families are heard in ASD research, including through prioritising topics and conducting research.[21]

Recommendation 10: The RACP supports funding for development of community-based research into the identification and diagnosis of ASD in Aboriginal and Torres Strait Islander families and how to better support their needs and aspirations.

Recommendation 11: The RACP believes that early identification of promising therapeutic interventions for people with ASD should be a priority for research funding.

The development of a National ASD Strategy and its interaction with the next phase of the National Disability Strategy (ToR I)

While the RACP is supportive of the development of a National Autism Strategy, it may be more productive to develop a broader strategy for children and adults neurodevelopmental conditions may more productive, rather than a narrow focus on ASD specifically.

Further, a strategy should only be considered if there is adequate support and plan to implement the plan and proceed to concrete action. As described throughout this submission, the most pressing need in this area at present is to ensure that assessment guidelines and treatment protocols are implemented in a flexible and inclusive manner that is appropriate for individuals across all NDB diagnoses and in all relevant settings.

Recommendation 12: The RACP recommends that if a National ASD Strategy is to be developed, it should have measurable targets and outcomes, that focus on improving life outcomes for people with NDB conditions, including ASD.
Priority areas within the strategy should include:

- implementing ASD national diagnostic guidelines;
- more effective support for females with ASD;
- addressing disparity in education attainment, employment and social inclusion. Specific targeting of groups who are further disadvantaged (e.g. people with intellectual disability) should be a feature; and
- taking a justice and equity approach for engaging/inclusion of Aboriginal and Torres Strait Islander peoples with ASD.

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[20] Kassem S, Oroszi T. Possible Therapeutic Use of Bumetanide in the Treatment of ASD Spectrum Disorder. Journal of Biosciences and Medicines. 2019;07(12):58-67.

[21] Lilley R, Sedgwick M, Pellicano E. WE LOOK AFTER OUR OWN MOB: Aboriginal and Torres Strait Islander Experiences of Autism [Internet]. Macquarie University; 2020. Available from: https://www.mq.edu.au/about/about-the-university/faculties-and-departments/faculty-of-human-sciences/departments-and-centres/department-of-educational-studies/news-and-events/news/news/first-report-into-autism-in-aboriginal-and-torres-strait-islanders-released,-revealing-shortage-of-supports-and-services/FINAL-REPORT-We-Look-After-Our-Mob_SCREEN.pdf