



Australian Government

Select Committee on Autism

Submission

Australian Government Department of Social Services
Australian Government Department of Education, Skills and Employment
Australian Government Department of Health

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This submission has been jointly prepared by the Departments of Social Services (DSS), Health, and Education, Skills and Employment (DESE), with input from the Attorney-General's Department and the Department of Industry, Science, Energy and Resources (DISER).

1 Introduction

- 1.1 Autism spectrum disorder (also simply termed autism) is a pervasive developmental disorder, characterised by symptoms evident from early childhood.¹ These symptoms can range on a spectrum from mild to severe, and include difficulty in social interaction, restricted or repetitive patterns of behaviour and impaired communication skills. However, these may not be recognised until later, when social demands, such as those related to schooling, become greater. There is no definitive test for autism; instead, diagnosis is made on the basis of developmental assessments and behavioural observations.
- 1.2 In 2018, the Australian Bureau of Statistics (ABS) reported² there were 205,200 Australians with autism, a 25.1 per cent increase from the 164,000 people with the condition reported in 2015. The number of people with autism in Australia has increased considerably in recent years, which has been attributed to increased awareness of the condition, changes in definitions, services and attitudes.
- 1.3 Boys are diagnosed with autism at 3.5 times the rate of girls, with prevalence rates of 1.3 per cent and 0.4 per cent respectively.³ However, Autism Awareness Australia notes this figure may hide the true incidence of autism in girls and women, with some estimates ranging from 7:1 to as low as 2:1 (that is, two boys diagnosed with autism for every girl).
- 1.4 Historically, states and territories have had responsibility for the majority of the service systems that support people with autism and their families and carers. This included early intervention assessments and supports (some now redirected into the National Disability Insurance Scheme (NDIS)), families and children's services (including playgroups and other means of supporting socialisation), and mainstream and specialised health and education services. States and territories retain responsibility for many of these systems, including primary health services (other than general medical practitioners) and education.
- 1.5 The Australian Government has supported state and territory governments' service delivery role, including by providing national leadership and encouraging the dissemination of best practice across state and territory systems. The Australian Government has also funded specific interventions, where there was an identified need and value in establishing a national approach, rather than duplicating the work of state and territory governments. For example, the Government has funded a range of programs for children with autism since 2008, including Positive Partnerships (part of the Helping Children with Autism initiative), which helps develop partnerships between the school and family to support school-aged children with autism.
- 1.6 Notably, the Australian Government had (and continues to have) direct responsibility for employment assistance programs, including specialised employment assistance for people with disability, including autism.
- 1.7 With the introduction of the NDIS, the Australian Government's role in supporting people with disability, including people with autism, has been enhanced. The NDIS is managed by the National Disability Insurance Agency (NDIA), as provided for under the *National Disability Insurance Scheme Act 2013* and relevant subordinate legislation.

- 1.8 The Australian Government is also working with state and territory governments on the development of a new National Disability Strategy for beyond 2020. The new Strategy will build on the achievements of the current strategy to create a more inclusive society that enables Australians with disability, including people with autism, to fulfil their potential as equal citizens.
- 1.9 The departments contributing to this submission acknowledge the COVID-19 pandemic represents a significant challenge in Australia and internationally, including for people living with disability. To ensure continuity of services for people with disability, the Australian Government is working with providers, peak bodies and stakeholders to anticipate and respond to the evolving challenges presented by COVID-19. While this submission provides general information about Australian Government supports for people with disability, including autism, supplementary information about the impact of COVID-19 on Government policy and programs may be provided to the Committee as the situation, and Government responses, continue to evolve.
- 1.10 Currently, the Australian Government provides a number of autism-specific supports and services to improve the lives of people with autism, their families and carers. Australian Government departments are also collaborating to provide supports designed to improve the health and wellbeing of all Australians, including Australians with disability.
- 1.11 The Australian Government works with state and territory governments to ensure Australia has a health system which is underpinned by the key foundational element of universal access to health care. Through Medicare, which supports free public hospital treatment, rebates for health services under the Medicare Benefits Schedule (MBS) and the Pharmaceutical Benefits Scheme (PBS), and specific health policies, programs, regulations and standards, the Australian Government seeks to build equitable health outcomes across population groups.
- 1.12 This submission provides a comprehensive snapshot of the Australian Government's policy framework and current funding, programs and policies to support people with autism, their families, carers and friends.

2 Policy and program context

- 2.1 Specific supports and services to improve the lives of people with autism and their families and carers that are funded by the Australian Government include:
 - Helping Children with Autism (HCWA) initiative – jointly delivered by DSS, DESE and Health;
 - Autism Specific Early Learning and Care Centres (ASELCCs) – DSS;
 - funding for Autism Spectrum Australia (ASPECT) under the Children and Parenting Support program – DSS;
 - initiatives to support people with autism into employment – DSS;
 - autism-specific health projects (such as CliniKids) – Health;
 - NDIA funding for the Autism Cooperative Research Centre (Autism CRC) to develop the National Guideline for the Assessment and Diagnosis of Autism in Australia, and work being funded by DSS to implement this guideline as the minimum national standard;
 - Research into autism, including research funded by the Autism CRC, the National Health and Medical Research Council (NHMRC) and the Medical Research Future Fund (MRFF).

- 2.2 Broader Australian Government supports for people with disability are also available and accessible to people with autism. Where known, this submission outlines the proportion of people with autism accessing these programs, however it should be noted that policy settings are evolving to shift focus from diagnosis as the access-point for services, to a more appropriate focus on understanding and addressing an individual’s functional needs, regardless of diagnosis. As such, many programs no longer collect data on diagnoses.

Supporting economic and social participation

- 2.3 Australia’s social support system is designed to improve people’s employment and social outcomes. People with autism, their families and carers are able to access programs and payments to support their economic and social participation. This includes:

- 2.3.1 **Disability Employment Services (DES) program**, which helps people with a range of disabilities to find and retain a job in the open job market.

At 29 February 2020, the DES program provided support to 10,862 participants with autism (including Aspergers syndrome (Aspergers)).⁴

- 2.3.2 **Disability Support Pension (DSP)**, which is an income support payment for people who are unable to work due to permanent physical, intellectual or psychiatric impairment.

As at 27 September 2019, there were 16,921 DSP recipients with a recorded medical condition of ‘Autistic Disorder’.

- 2.3.3 **Other income support payments**, such as the JobSeeker Payment, Youth Allowance (other), Carer Allowance and Carer Payment, where an individual with autism meets the eligibility criteria for these payments. Data on individuals with autism in receipt of an income support payment is provided at **Attachment B**.

- Note: On 20 March 2020, the JobSeeker Payment replaced the Newstart Allowance as the main income support payment for recipients aged between 22 years to Age Pension qualification age who have capacity to work. The JobSeeker Payment is available to people who are looking for work, who temporarily cannot work or study because of an injury or illness, or bereaved partners in the period immediately following the death of their partner, subject to meeting eligibility requirements.

- 2.4 More information on programs and payments that support the economic and social participation of people with autism is provided at **Attachment C**.

National Disability Insurance Scheme

- 2.5 The NDIS provides a world first approach to the provision of disability support that puts people with disability at the centre of decision-making enabling the individual choice and control over the use of funds provided for reasonable and necessary supports. As at March 2020, the NDIS was supporting close to 113,500 participants with autism, which represents 31 per cent of all participants – the largest disability group in the NDIS.

- 2.6 From 1 July 2020, the NDIS became available nationally. As part of this, Australian Government disability programs have been transitioning funds and clients to the NDIS, including the individualised components of the autism-specific HCWA program. The majority of clients are expected to transition to the NDIS, and DSS is working closely with the NDIA and service providers to support clients to test their eligibility for the NDIS as early as possible, to prevent any gaps in funded supports and services.
- 2.7 Clients who access HCWA individualised funding and are not eligible for the NDIS, will receive Continuity of Support (CoS). To be eligible to receive CoS, clients will be required to have tested their eligibility for the NDIS and been found ineligible.
- 2.8 While the NDIS provides assistance to people with disability, it does not replace all services for people with disability that were previously funded by state and territory governments. Nor does it remove the responsibility of state and territory governments, industry, business and community organisations to continue supporting service approaches that ensure inclusion, accessibility and connection for all people with disability, including people with autism, whether or not they are eligible for the NDIS.

Legislative framework

- 2.9 The *Disability Discrimination Act 1992* (the DDA) makes direct and indirect discrimination on the basis of disability unlawful in key areas of public life, such as employment, education, the provision of goods, services and facilities, and the implementation of federal laws and programs. The DDA also contains a duty to make reasonable adjustments and expressly prohibits harassment in employment, education and the provision of goods and services.
- 2.10 The Australian Human Rights Commission (AHRC) is an independent statutory body that can receive, investigate and attempt to conciliate complaints of unlawful discrimination, including complaints made under the DDA.
- 2.11 The DDA is supplemented by disability standards. Section 31 of the DDA allows the Attorney-General to make disability standards in relation to unlawful discrimination. The standards give further precision to the rights and obligations under the DDA about equal access and provide greater certainty about how to comply with the legislation. There are three standards currently in force including the Disability Standards for Education 2005 (Education Standards).
- 2.12 In addition, each state and territory has legislation that prohibits discrimination on the basis of disability. The state and territory legislation makes discrimination on the basis of disability unlawful in a number of areas of public life including employment, education, access to places and vehicles and the provision of goods, services and facilities. The legislation is administered by state and territory bodies who exercise functions under the legislation, including investigating and conciliating complaints.
- 2.13 Australian Government anti-discrimination laws address the possibility of incompatibility with state and territory anti-discrimination laws by specifying that they are not intended to exclude or limit the operation of the state and territory laws that are capable of operating concurrently.

- 2.14 The *Disability Services Act 1986* (the DSA) provides a legal framework for the Australian Government to fund eligible organisations and states and territories to provide services for people with disability. The DSA, through subordinate legislative instruments, provides principles, objectives, standards and guidelines relating to accreditation, resourcing and delivery of quality disability services. Authority for some payments, including the provision of funding for Disability Employment Services (referenced in paragraph 2.3.1 of this submission and Attachment C: Table 6 at C.4.5), comes from the DSA.

Future policy beyond 2020

- 2.15 Work is underway to shape the future of policy to create a more inclusive society that enables Australians with disability, including people with autism, to fulfil their potential as equal citizens. This includes:

2.15.1 The current **National Disability Strategy 2010-2020** (the Strategy) provides a ten-year national policy framework for improving the lives of all people with disability, their families and carers. It outlines the outcome areas agreed by all levels of government for all people with disability and does not distinguish between cohorts (for example, disability types).

2.15.2 The term of the current Strategy will finish at the end of 2020 and governments across Australia are working together to design a new National Disability Strategy to replace the current one. The Strategy is a shared commitment by all governments to work together to improve outcomes for the 4.4 million Australians with disability.

Ongoing engagement with people with disability is core to the development of the new Strategy. People with autism actively participated in the first stage of consultation to inform the development of the Strategy. There will be further opportunities to incorporate the perspectives of the autism community through the next phase of consultations, which will take place before the new Strategy is finalised.

The Australian Government is developing a position paper with the states and territories to inform the second stage of consultations. This paper sets out the proposed features of a new National Disability Strategy. The position paper also articulates the important role governments, industry and community play in breaking down the barriers that limit the social and economic inclusion of people with disability.

2.15.3 The Government has also provided \$300,000 in funding for Reimagine Australia (formerly known as Early Childhood Intervention Australia (ECIA)) to develop the **Reimagine Early Childhood: A National Action Plan to Improve Outcomes for Children with Disability and Developmental Delay** (the Reimagine Action Plan) (formerly known as the National Blueprint for Early Childhood Intervention).

The Reimagine Action Plan will focus on understanding the current state of the early childhood intervention sector, including the challenges and opportunities facing the sector adapting to the NDIS. The Reimagine Action Plan will also consider opportunities to build the knowledge and capacity of families and the sector to identify developmental concerns at the earliest possible stage, including considering how to strengthen collaboration between the health and other systems and early childhood intervention services.

Families and carers of children with autism are highly likely to engage with early intervention services to access supports to improve their child's development and

outcomes. The findings and recommendations of the Reimagine Action Plan are intended to respond to feedback from families and early intervention services, in order to ensure a service system that is collaborative and has capacity to provide high quality (evidence-based) supports that meet the needs of families of children with disability and developmental delay.

Reimagine Australia is consulting with the NDIA and DSS, along with sector leaders, service providers, and parents and carers to develop the Reimagine Action Plan. Reimagine Australia engaged with the autism community as part of consultations to inform the Reimagine Action Plan, including families of children with autism and other neurodevelopmental and behavioural conditions, autism service providers, specialists and advocates. The Reimagine Action Plan will be delivered to Government in 2020.

3 Helping Children with Autism initiative

3.1 Helping Children with Autism (HCWA) was introduced in 2008, as a joint initiative between the then Departments of:

- Families, Housing, Community Services and Indigenous Affairs (FaHCSIA – now DSS);
- Education, Employment and Workplace Relations (DEEWR – now DESE); and
- Health and Ageing (DoHA – now Health).

3.2 The HCWA initiative was designed to improve access to best practice early intervention, education and support for families and carers of children with autism. The HCWA initiative includes:

- Individualised funding for early intervention (DSS);
- Block-funded community and referral services (DSS);
- HCWA Medicare Items (Health); and
- Positive Partnerships program to support school-aged children with autism (DESE).

3.3 These components are explained in more detail below.

Individualised funding for early intervention (DSS)

3.4 The individualised funding component of HCWA is for children diagnosed with autism from birth to six years old. Eligible families can access up to \$12,000 in funding to use on early intervention supports and resources through a registered panel of Early Intervention Service Providers. Parents are also able to choose the service providers and therapeutic services that best meets their child's needs. Up to 35 per cent of a child's HCWA funding may be used to purchase resources that contribute to the child's early intervention needs. An additional \$2,000 is provided to help families who live in a regional or remote locality with transport costs associated with accessing providers, for example, travel costs.

3.5 The funding supports delivery of multi-disciplinary, evidence-based early intervention to facilitate improved cognitive, emotional and social development for children accessing HCWA. Early intervention supports aim to address issues such as child development, communication, socialisation and behaviour. The early intervention approach can foster significant improvement in life outcomes for the child and their family, improve the child's ability to transition into a mainstream education setting and provide parents and carers with tools to build their own capacity to meet their child's needs.

- 3.6 Since the inception of HCWA in 2008, almost 65,000 children have accessed individualised funding for early intervention supports and therapeutic services.
- 3.7 The individualised funding component of HCWA is due to fully transition to the NDIS. To support the transition of HCWA clients to the NDIS, DSS is working with the NDIA and Autism Associations to ensure families and carers are informed and supported to make an NDIS access request.
- 3.8 HCWA clients who are ineligible for the NDIS may be eligible to access Continuity of Support.

Block-funded programs (DSS)

- 3.9 HCWA also provides several block-funded program components that offer families early intervention information, services and supports. These are designed to complement individualised funding and help families to support their child as early as possible. The block-funded components include:

- 3.9.1 **Autism Advisor Service:** Autism Advisors are responsible for registering eligible children for HCWA funding, and providing advice, information and support to families following a child's diagnosis. Autism Advisors are often a family's first point of contact for HCWA.

With the roll-out of the NDIS and closure to new registrations, Autism Advisors are now focused on liaising with Early Childhood partners and the NDIA to support families to make a smooth transition to the NDIS.

- 3.9.2 **HCWA Early Days Workshops:** The Early Days Workshops are structured information sessions providing information and support to parents and carers of pre-school and school-aged children with autism or autism-like symptoms. Education and support workshops provide a national program of information that includes practical strategies to assist parents and carers.

There is no cost to attend an Early Days Workshop. They are open to families who have a child who has not yet been diagnosed but is exhibiting symptoms of autism. Since 2011, around 3,300 workshops have been delivered nationally for more than 26,500 parents and carers.

- 3.9.3 **HCWA Early Days Workshops National Coordinator:** The Early Days Workshops National Coordinator provides support to state and territory workshop coordinators and ensures consistency across workshops and materials distributed nationally.

The National Coordinator has facilitated the delivery of about 680 specialised workshops and forums for more than 1,900 participants since 2011, including tailored workshops delivered in Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. Additionally, the National Coordinator performs an administrative role executing development, evaluation and review of the workshops nationally.

- 3.9.4 **PlayConnect Playgroups:** PlayConnect Playgroups are facilitated playgroup activities for children with autism or autism-like symptoms, and their siblings. These playgroups also provide an informal networking space for parents and carers, and offer support to the family unit by including parents and siblings.

Playgroup Australia delivers 42 PlayConnect Playgroups across Australia each year. The playgroups are free to attend and have been attended by hundreds of families.

Separate to the HCWA package, DSS also funds Playgroup Australia to resource, support and sustain local community playgroups that provide play opportunities and parenting and family support. These playgroups are available to all families, including but not limited to families with children or parents with a disability. Playgroups provide place-based supports, linkages and membership services to families, community playgroups and organisations that deliver community playgroups.

- 3.9.5 **Raising Children Network (RCN) – Autism Web Content:** RCN is a web-based parenting skills, child health and development resource that provides information for Australian parents from pregnancy through to raising teenagers generally. In addition to general parenting advice, RCN provides information specific to autism, early childhood early intervention and children with disability, including in relation to the NDIS.

The site provides high quality, evidence-based, accessible and practical online support. Web content is periodically reviewed and updated to ensure the information is accurate, current and relevant. RCN maintains over 300 holistic disability and autism-specific resources on topics such as behaviour, development and family life. This includes 16 resources specific to NDIS and early childhood early intervention and about 120 other resources linking to NDIS-related information. Traffic to the site is consistently high, with 20.5 million visits and 31.5 million pages read between 2018 and 2019.

- 3.9.6 **Early Intervention Indigenous Liaison Officers (ILOs):** The ILO program aims to increase awareness of childhood disability in Indigenous families and communities, assist access to diagnosis and refer families and carers to culturally relevant information and support services.

The program is for Indigenous families with a child with a disability or suspected disability and their communities. ILOs also work to ensure service providers can help families to navigate the system in a safe and culturally appropriate way. Autism Queensland administers the ILO program nationally.

HCWA Medicare Items (Health)

- 3.10 The Department of Health implemented new Medicare items on 1 July 2008 for consultant paediatricians (item 135) or psychiatrists (item 289), on referral from another medical practitioner, to provide early diagnosis and treatment of autism or any other pervasive development disorder (PDD) for children under 13 years of age. The items are for assessment, diagnosis and creation of a treatment and management plan, including patient referral for MBS subsidised:

- allied health assessment services (items 8200-82030 - maximum 4 services); and
- allied health treatment services (items 82015-82035 - maximum 20 services).

- 3.11 Items 135 or 289 also provide a referral pathway for access to services provided through the block-funded Autism Advisor Service by DSS.

- 3.12 In addition to referrals to allied health treatment services, a consultant paediatrician or psychiatrist can refer a child to an eligible allied health provider to assist with diagnosis of the child or for the purpose of treating the child's PDD. Referrals for these allied health assessment services can be made by a consultant paediatrician or psychiatrist as an outcome of the service provided under one of items 110-131 or 296-370 inclusive.

- 3.13 Medicare rebates cover a portion of the fee for the service, although providers may accept the patient rebate value as the sole payment for the service (bulk-billing).

- 3.14 It is important to note that 20 visits are the total number of Medicare claimable treatment sessions available to each eligible child through the HCWA program up to the age of 15 years – rather than an annual entitlement. The number of services necessary to make measurable gains may be more or less than the 20 visits that can be subsidised through HCWA.
- 3.15 The HCWA Medicare items will continue to be available beyond 30 June 2020. Data on service volume for each relevant Medicare item is provided at **Attachment A**.

Positive Partnerships program to support school-aged children on the autism spectrum

- 3.16 The education-related component of the HCWA initiative is delivered through the Positive Partnerships program. Positive Partnerships aims to build partnerships between schools and families to improve the educational outcomes of students with autism. It provides:
- professional development for teachers, principals and other school staff to build their understanding, skills and expertise in working with school-age students with autism;
 - workshops and information sessions for parents and carers of school-age students with autism; and
 - a website providing online learning modules and other resources. The website includes:
 - a range of resources, in different languages, for parents and carers from culturally and linguistically diverse backgrounds
 - resources developed in consultation with Aboriginal and Torres Strait Islander communities.
- 3.17 About half of the schools and participants are from regional and remote areas.
- 3.18 Since the 2007-08 Federal Budget, more than \$91 million has been allocated for support for school students with autism through the Positive Partnerships program. This includes:
- \$20.8 million for Phase 1 (2008-2011)
 - \$19.2 million for Phase 2 (2012-2015)
 - \$30.2 million for Phase 3 (1 October 2015 to 31 December 2020)
 - \$21 million for Phase 4 (2021-2024).
- 3.19 So far in Phase 3, from 1 October 2015 to 31 December 2019, more than 37,600 people have participated in face-to-face and online training. There have been more than 25,500 completions of online courses by both teachers and parents and carers. The Positive Partnerships Facebook page has an average weekly post reach of 35,000. The Positive Partnerships website and online learning hub has received more than 534,000 hits since December 2016. It has recently been upgraded to enable access on mobile devices to support the widest possible access.
- 3.20 In May 2016, the program was expanded through collaboration with the Autism CRC at the University of Queensland and through an extension of outreach to families disadvantaged by distance and language. This facilitated a consolidation of outreach initiatives to Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities, where the incidence of children on the autism spectrum tends to be under diagnosed and under reported.

4 Other autism-specific supports

Autism Specific Early Learning and Care Centres

- 4.1 Between 2008 and 2010, six Autism Specific Early Learning and Care Centres (ASELCCs) were established jointly by the then FaHCSIA and the then DEEWR, as an additional commitment to the HCWA initiative. The centres were established to provide high quality and affordable early intervention programs, and specific support to children aged from birth to six years old with autism or autism-like symptoms in a long day care setting. As at June 2019, 1,488 children have attended an ASELCC across Australia.
- 4.2 ASELCCs also provide families with education and support to use early intervention strategies in the home to maximise the positive impact on children's long-term outcomes. The long day care model allows parents the opportunity to participate more fully in education, employment and the community.
- 4.3 Through affiliations with universities or hospitals, the ASELCCs have a research and workforce-training component that:
 - delivers research into better understanding autism and evidence-based interventions; and
 - increases workforce capacity by developing resources to enable the mainstream childcare sector to support children with autism, and providing tertiary students with learning opportunities.
- 4.4 Over their 10 years of operation, the ASELCCs have established themselves as local sources of trusted best practice autism advice and have built partnerships with a range of organisations, including research institutions, mainstream childcare centers and community groups.
- 4.5 Funding from DSS for a child's placement in an ASELCC is due to cease in line with the rollout of the NDIS, whereby ASELCCs will need to source their ongoing funding through providing services to NDIS participants. The ASELCCs have been undertaking reviews and business modelling to prepare themselves for the transition to the NDIS, and ASELCCs in some states are already receiving revenue from charging for services for children in the NDIS with approved NDIS plans. The ASELCCs will continue to work closely with DSS and the NDIA to ensure a smooth transition.

Children and Parenting Support program

- 4.6 Around \$330,000 in funding has been provided under the Children and Parenting Support (CaPS) program each year since 2015 to ASPECT for the provision of parent education and skills, home visits and peer support groups for children and families impacted by autism. ASPECT services are located in the Richmond Valley and Tweed Heads in NSW.
- 4.7 The broader CaPS program is designed to provide early intervention and prevention support to children and their families. Services seek to identify issues such as risk of neglect or abuse, within families, and provide interventions or appropriate referral(s) before these issues escalate.
- 4.8 While not autism-specific, CaPS services increase the capacity of parents, carers and grandparent carers, which in turn helps to improve children's wellbeing and development. CaPS provides a range of services including supported playgroups and school readiness programs, targeted at supporting child development, as well as parenting skills courses and peer support groups to build the capacity of parents and carers.

Supporting people with autism into employment

- 4.9 DSS is working to implement the 2019 Election Commitment to ‘Support people with autism into employment’. This commitment provides \$2 million to support people with autism to find and keep a job, and consists of two parts:

- 4.9.1 **\$1.5 million to expand the Dandelion Program**, in partnership with DXC Technology – focused on sustainable employment, the DXC Dandelion Program supports people with autism to develop their technical, life and executive functioning skills to increase employability and pursue careers in information technology.

This project will be trialed across two urban and two regional areas and will target six DES providers. Through these providers, the trial aims to target 30 employers and 60 DES participants with autism. The project will test the scalability of tools and modules from the Dandelion methodology to integrate into the current DES process. If successful, it could lead to a wider integration of the Dandelion methodology into DES.

- 4.9.2 \$500,000 for initiatives to encourage employers to become autism-confident. Processes to allocate this funding are currently underway.

- 4.10 Funding to implement this Election Commitment is expected to be expended over 2019-20 to 2021-22.

Autism-specific health projects

- 4.11 In addition to the support outlined under the HCWA initiative above, there are a range of Australian Government health initiatives to support people with autism. This includes broader support through accessing MBS items, support through Primary Health Networks, and investment in health and medical research.

CliniKids

- 4.12 The Telethon Kids Institute has established CliniKids, a bespoke, state-of-the-art clinic, designed specifically to meet the needs of children with autism.
- 4.13 CliniKids provides clinical services such as speech therapy, psychology, occupational therapy and diagnostic assessments to children aged from birth to 12 years with developmental delays and/or autism.
- 4.14 In 2018-19, the Australian Government contributed \$600,000 to support the establishment of CliniKids. The total cost of the project was \$1.35 million, with the remainder of funds provided by the Telethon Kids Institute.

MBS Review Taskforce

- 4.15 The MBS Review Taskforce is reviewing the clinical effectiveness of current services, and when finalised will make recommendations to the Government to better address the needs of the community.

4.16 The MBS Review Taskforce is currently considering a range of draft recommendations to the Australian Government which focus on:

- improving access to complex paediatric allied health assessments for children with potential autism spectrum disorder, complex neurodevelopmental disorder or eligible disability diagnosis; and
- encouraging increased multidisciplinary planning for children with potential autism spectrum disorder eligible disability diagnosis.

4.17 The MBS Review Taskforce is expected to provide its final advice to Government later in 2020.

5 Education policies and programs

Legislative framework

- 5.1 Support for students with autism is underpinned by the Disability Standards for Education 2005 (the Education Standards), subordinate legislation to the *Disability Discrimination Act 1992* (the DDA).
- 5.2 The Education Standards operate to clarify the obligations of education and training providers and the rights of students with disability under the DDA.
- 5.3 In addition, the DDA contains a duty to make reasonable adjustments for people with disability where this will not cause unjustifiable hardship for the education provider. This is a positive obligation on duty holders to take practical steps to address disadvantage experienced by a person with a disability. The duty applies to all education providers, public and private.
- 5.4 The Education Standards provide a framework to ensure that students with disability are able to access and participate in education on the same basis as other students. All jurisdictions, education sectors and providers are required to comply with the Education Standards.
- 5.5 The third review of the Education Standards is underway. The review will examine the effectiveness of the Education Standards in achieving their objective, including an examination of the Australian Government responses to recommendations to the 2010 and 2015 reviews.

Funding, policies and programs

- 5.6 The Australian Government provides support for people with autism across their learning journey from childcare to early learning to school and for tertiary education, including:
 - the Positive Partnerships program to support school-age students with autism (see paragraphs 3.16-3.20);
 - support in early childhood education and care (ECEC) through the Inclusion Support Program;
 - funding for school students with disability based on the levels of adjustment reported under the Nationally Consistent Collection of Data on School Students with Disability (NCCD);
 - programming and funding for student wellbeing through the Australian Student Wellbeing Framework and other initiatives;
 - training and support for teachers; and
 - funding and programming to support students with disability in tertiary education.

Inclusion Support Program

- 5.7 The Inclusion Support Program supports eligible ECEC services to improve their capacity and capability to provide quality inclusive practices for children with additional needs, including those with disability, in mainstream services.
- 5.8 The Inclusion Support Program includes:
- Inclusion Agencies: A state and territory wide network of seven Inclusion Agencies provide tailored support to ECEC services and access to a Specialist Equipment Library.
 - Inclusion Development Fund: Provides funding support to assist eligible ECEC services to address barriers to inclusion that cannot be resolved by Inclusion Agencies' support. This may include funding for an additional educator to assist in the care environment.
- 5.9 The Inclusion Support Program also assists services to implement a quality, inclusive and equitable practice under the National Quality Framework and in line with the National Quality Standard.
- 5.10 State and territory governments also provide a range of funding to support children with disability in state government funded preschool settings.

Nationally Consistent Collection of Data on School Students with Disability

- 5.11 Funding for school students with disability is based on the levels of adjustment reported under the NCCD.
- 5.12 The NCCD focuses on the level of adjustment provided to a student based on their functional needs, rather than disability type. The collection captures all students receiving adjustments to support their access and participation in learning due to a disability – not just those with a medical diagnosis. It aligns to education authorities' obligations to provide reasonable support to enable students with disability to access education, as set out under the DDA and the Education Standards.
- 5.13 The annual collection is more than a count of students with disability – it aims to ensure support becomes routine by strengthening the schools' understanding of their legislative obligations by:
- focusing on what students with disabilities need to participate in learning on the same basis as other students; and
 - strengthening communication between schools, parents and the broader community to reinforce an ongoing culture of inclusion and support for students with disability.
- 5.14 The Australian Government has allocated \$20 million over four years to strengthen and quality assure the NCCD across all sectors under the NCCD Continuous Improvement Measure. This includes the development of a web-based portal, which went live in February 2019, to provide all schools nationally with free information and professional learning resources to support students with disability (www.nccd.edu.au).
- 5.15 The portal contains a range of resources for teachers specifically about autism, including:
- advice on common classroom adjustments that teachers can make to support students with autism; and
 - case studies involving students with autism.

- 5.16 The Positive Partnerships program is collaborating with Education Services Australia, to produce additional resources for the portal relating to students from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities.

Schools funding and student with disability loading

- 5.17 The Australian Government supports schools through needs-based funding to provide quality educational opportunities to all Australian students, including students with autism.
- 5.18 The Australian Government is providing an estimated \$314.2 billion investment in recurrent funding to all Australian schools from 2018 to 2029. This includes funding for government schools, Catholic schools and independent schools.
- 5.19 Alongside the Australian Government's increased investment, state and territory governments are also required to deliver their share of total public funding.
- 5.20 In accordance with the *Australian Education Act 2013*, Australian Government funding is calculated with reference to a school's Schooling Resource Standard (SRS), with a SRS base amount along with six loadings to support disadvantaged schools and facilitate achievement of priority cohorts, including the student with disability loading.
- 5.21 From 2018 to 2029 an estimated \$29.6 billion will be provided for the student with disability loading nationally.
- 5.22 Since 2018, the calculation of the student with disability loading has been based on the NCCD, which gives a national definition of a student with disability and the level of support they need to access and participate in learning.
- 5.23 The Government expects schools and school systems to consider their funding from all sources – Australian, state and territory governments and private organisations – and to prioritise their spending to meet the educational needs of all of their students.
- 5.24 The Government is not prescriptive about how school authorities or individual schools spend Australian Government funding. Under the *Australian Education Act 2013*, all school systems have the flexibility to distribute funds according to their own needs-based arrangements. This allows system authorities to target resources appropriately to address local needs, including the needs of students with disability.

Australian Student Wellbeing Framework

- 5.25 Student wellbeing is a critical factor in optimising learning and school engagement. The Australian Wellbeing Framework (the Framework) describes the elements required for the whole school community to build and maintain safety, positive relationships and wellbeing. The five elements of the Framework – leadership, inclusion, student voice, partnerships and support – prioritise the need to adapt policies and practices to meet the diverse needs of all students within a school community.
- 5.26 The Framework has a particular emphasis on including the voices of students in decision making, to ensure that the needs of students and their families are a central focus. This emphasis on inclusion and participation encourages schools to listen to the voices of students with disability so that reasonable adjustments can be made to meet their needs.

Measures against bullying

- 5.27 The 2018 Australian Autism Educational Needs Analysis by the Autism CRC indicated that coping with bullying and teasing was one of the top ten issues for students with autism.
- 5.28 The Australian Government is progressing national strategies to prevent and mitigate bullying in schools by:
- building a shared understanding of what bullying is (and is not) to enable communities to prevent and respond to it. For example, fact sheets for parents, carers and students about the different types of bullying and how to recognise the signs are published on the Bullying. No Way! website;
 - providing resources to students, parents and educators to help protect against bullying. For example, the Student Wellbeing Hub website (www.studentwellbeinghub.edu.au/) provides access to resources on topics such as Protecting Against Bullying and Building Positive Relationships;
 - empowering students and educators to find workable solutions to address bullying and violence in their school communities through the National Day of Action Against Bullying and Violence which provides an opportunity for school communities to pledge their commitment to address bullying and violence;
 - changing community attitudes to violence and abuse by developing educational resources to build respectful relationships, under the Educating against Domestic Violence initiative as part of the Women's Safety Package for schools; and
 - facilitating national implementation of the education-related recommendations of the Royal Commission into Institutional Responses to Child Sexual Abuse, such as nationally consistent curriculum for online safety education in schools, pre-service education and in-service staff professional learning to help create safe online environments.

Support for teachers

- 5.29 The Australian Institute for Teaching and School Leadership (AITSL), established by the Australian Government, has developed the Australian Professional Standards for Teachers (the Teacher Standards). The Teacher Standards require teachers to be able to support full participation of students with disability and to differentiate teaching to meet the learning needs of students across the full range of abilities.
- 5.30 The Teacher Standards include a number of domains relevant to teaching students with disability, aiming to ensure that all teachers are well prepared to support inclusive student participation and engagement with education.
- 5.31 AITSL also provides accessible, practical tools to the teaching profession which support teacher improvement and professional learning. For example, Illustration of Practice resources support teachers to understand how their current practice is aligned to the Teacher Standards and supports their professional learning and development.
- 5.32 While the Australian Government plays a leadership role in school education, registration is the responsibility of teacher regulatory authorities in each state and territory, consistent with nationally consistent standards.
- 5.33 A key recommendation of 2018 Australian Educational Needs Analysis concerned the need for a flexible and individually tailored educational approach to programming and support for students with autism.

- 5.34 The Australian Government is committed to improving the effectiveness and capability of the teaching profession, enhancing the skills to teach all learners, including students with autism.
- 5.35 The Australian Professional Standard for Principals (the Principals Standard) provides a framework to define the role of the principal, explain their professional practice in common language, and makes explicit the role of quality school leadership in improving learning outcomes. In particular, the Principals Standard sets out the principals' role in engaging and working with the community, embracing inclusion and supporting the needs of students, families and carers facing complex challenges.
- 5.36 Further information on the Teachers Standards and Principals Standard is at: www.aitsl.edu.au.

Funding and support for students in tertiary education

- 5.37 Funding to assist domestic students with disability, including those with autism, to access higher education is provided through the Higher Education Disability Support program.
- 5.38 This program received funding of \$7.7 million in financial year 2018-19 with about \$6.3 million paid to eligible higher education providers to reimburse 50 per cent of the costs of education and equipment support for students with disability with high cost needs.
- 5.39 Funding is also provided for:
- **Australian Disability Clearinghouse on Education and Training website:** Provides information, advice and online resources to disability practitioners, teachers and students with disability on inclusive teaching and learning practices.
 - **National Disability Coordination Officer Program:** about \$4.4 million in funding is provided annually to assist people with disability to transition from school to tertiary education and subsequent employment.
 - **Australian Industry Skills Committee:** The Committee has commissioned work to improve the training outcomes of persons with disabilities in vocational education and training (VET).
- 5.40 The **National Centre for Vocational Education Research (NCVER)** has produced a "Good Practice Guide: Supporting tertiary students with a disability or mental illness". This guide is designed to assist teaching staff and disability services staff in VET and higher education institutions to offer individualised or institution level adjustments in teaching, learning and assessment methods to support students with disability or ongoing ill health. The guide is available on the NCVER website: www.ncver.edu.au/research-and-statistics/publications/all-publications/supporting-tertiary-students-with-a-disability-or-mental-illness-good-practice-guide.
- 5.41 Registered training organisations (RTOs) delivering nationally recognised VET are required to comply with the **Standards for Registered Training Organisations (RTOs) 2015**. Under these Standards, RTOs need to determine the support needs of students and provide access to educational and support services as necessary. Examples of educational support services include providing equipment, resources and/or programs to increase access for learners with disabilities and other learners in accordance with access and equity principles.

- 5.42 The **Australian Skills Quality Authority (ASQA)** is the national VET regulator and seeks to ensure the VET sector’s quality and reputation is maintained through effective regulation. ASQA has developed information and guidance for RTOs and other stakeholders in relation to providing quality training and assessment services to students with disabilities. This information is at: www.asqa.gov.au/resources/fact-sheets/providing-quality-training-and-assessment-services-to-students-with-disabilities.
- 5.43 **Attachment C** of this submission contains further information on additional measures provided by DESE to support students with autism with training and entry into the workforce.
- Australian Apprenticeships Incentives Program (AAIP) (refer to C.4.20)
 - Disability Australian Apprentice Wage Support (DAAWS) (refer to C.4.20)
 - Off-the-job Tutorial, Mentor and Interpreter Assistance (refer to C.4.20)
 - jobActive (refer to C.4.1).

6 Support for people with autism through the NDIS

- 6.1 The NDIS is the most significant social reform of its kind since the introduction of Medicare. It was established in 2013 through the *National Disability Insurance Scheme Act 2013* (NDIS Act) and represents a social insurance model of care for eligible Australians with disability.
- 6.2 The NDIS provides eligible Australians with a permanent and significant disability access to the reasonable and necessary supports they need to achieve their goals and aspirations. In addition, the NDIS can provide all people with disability with information and connections to services in their communities such as doctors, sporting clubs, support groups, libraries and schools, as well as information about what support is provided by each state and territory government.
- 6.3 The NDIS is not intended to replace all the services and supports provided elsewhere in government or the community. While the NDIS is designed to benefit all Australians with disability, only a small proportion will become NDIS participants. Of the estimated 4.4 million Australians with disability, around 500,000 (those people with a ‘permanent and significant’ disability) will receive individualised supports under the scheme.
- 6.4 As outlined in the National Disability Strategy 2010-2020, ensuring inclusion of people with disability in their community and enabling them to access the supports they need to realise their full potential is a shared responsibility of all Australian governments, non-government organisations, businesses and the wider community.
- 6.5 At March 2020, the NDIS is supporting close to 113,500 participants with autism. People with autism represent 31 per cent of the total number of participants in the NDIS, making it the largest disability cohort in the NDIS.
- 6.6 The Australian Government is committed to improving outcomes for people with disability under the NDIS, making NDIS processes simpler and more straight-forward, and introducing a new NDIS Participant Service Guarantee (the Guarantee) into law.
- 6.7 In June 2019 the Australian Government commissioned Mr David Tune AO PSM to undertake an independent review of the NDIS Act (the Tune Review). The Tune Review sought to identify opportunities to amend the NDIS Act to remove process impediments, increase the efficiency of the scheme’s administration and implement the Guarantee.

- 6.8 The Tune Review was informed by broad national public consultation. Mr Tune delivered his final report to the Australian Government in December 2019, making 29 recommendations aimed at streamlining and improving the participant and provider experience. The Australian Government is currently considering all of the Tune Review recommendations, with a view to updating and clarifying the legislation, implementing the Guarantee and removing barriers to positive participant and provider experience.
- 6.9 The Australian Government is committed to bringing the Guarantee and any other agreed recommendations into law as soon as possible. The Australian Government is consulting with people with disability, ensuring the voices of people with disability are heard. The Australian Government will provide further information on the release of the Government response to the Tune Review and the legislation giving effect to the Guarantee, shortly.
- 6.10 The NDIA is preparing a separate submission to the Select Committee on Autism to provide further detail about how the Scheme operates to support people with autism, and may expand on some of the matters outlined below.

Early Childhood Early Intervention approach

- 6.11 Early intervention supports for a child with a developmental delay or disability in their early years is critical to achieving the best long term outcomes.
- 6.12 Under the NDIS, the Early Childhood Early Intervention (ECEI) approach supports children aged from birth to six years who have a developmental delay or disability as well as their families and carers. The ECEI approach is designed to individually determine and facilitate the most appropriate support pathway for each child, regardless of their diagnosis.
- 6.13 The ECEI approach helps children develop the skills they need to take part in daily activities and achieve the best possible outcomes in their daily life. Supports delivered under ECEI do not replace the responsibilities of mainstream service systems to cater for the needs of children with disability. For example, the early childhood education and care (ECEC) sector has ongoing responsibility for meeting the education and care needs of children with a developmental delay or disability, including building the capacity of ECEC services to provide inclusive education and care to children.
- 6.14 The ECEI approach is intended to uphold the eligibility criteria of the NDIS, while helping to ensure that less severe cases are supported outside of the NDIS.
- 6.15 Depending on their individual circumstances, the ECEI approach provides families and carers with a combination of information, referral to mainstream services and short-term intervention. Each child and family accessing ECEI will have unique service and support needs. As such, the NDIA has engaged Early Childhood Partners, who are experienced in intervention, to help deliver the ECEI approach Australia wide.
- 6.16 Early Childhood Partners tailor support to individual needs for children aged between birth and six years, and provide families and carers with information and connections such as:
- information about appropriate supports in the local area;
 - guidance to help families make decisions about the right supports and services for their child;
 - provision of short-term early intervention (where appropriate); and
 - where a child requires longer-term supports – assistance with applying to access the NDIS, developing a plan, and connecting with providers.

- 6.1 All children aged 0-6 can access Early Childhood partners. As at 31 March 2020, there were 55,957 children aged 0-6 with an approved NDIS plan.
- 6.2 In addition, as at 31 March 2020, there were 9,956 children aged 0-6 in the ECEI gateway:
 - 4,761 children had already commenced receiving initial supports (including but not limited to: information, linkages, therapy, access support, family support and mainstream capacity building); and
 - 5,195 children receiving support for ongoing engagement, assessment and screening for needs and to provide families and carers with information, emotional support and connections.
- 6.3 Some children will be receiving initial supports while waiting for a decision on an access request, with close to 700 children per week proceeding to an ‘access met’ decision. On average, children and their family can access initial supports within 12 days.
- 6.4 The number of children aged 0-6 with a primary disability of autism as at 31 March 2020 is 19,180. This includes:
 - 19,066 children with approved plans with a primary disability of autism.
 - 114 children receiving initial supports in the ECEI gateway with a primary disability of autism.

NDIS Mainstream Interfaces

- 6.5 The Australian Government and state and territory governments continue to clarify the interface between the NDIS and funding and delivery responsibilities across a number of key service systems, including health; mental health; early childhood development; child protection and family support; school education; higher education and VET; employment; housing and community infrastructure; transport; justice; and aged care.
- 6.6 These service systems provide support to all Australians as part of each system’s universal service obligations (for example, meeting the health, education, housing, or safety needs of all Australians) or covered by reasonable adjustment (as required under the *Disability Discrimination Act 1992*, Disability Standards or similar legislation in jurisdictions). Being an NDIS participant does not preclude a person from seeking support from these systems and disability systems concurrently however, they will not be able to access the same funded services under more than one program at the same time.
- 6.7 The distinction between the responsibilities of the NDIS and each of the various systems and the ability to receive support concurrently, are addressed in the Applied Principles to Determine the Responsibilities of the NDIS and other Service Systems’ (the APTOS principles) which were agreed by governments on 27 November 2015. Significant effort is being made, in conjunction with states and territories, to address how these different mainstream services interact with the NDIS.
- 6.8 Progress to date has included:
 - introduction of Justice Liaison Officers (JLOs) by the NDIA to work across state and territory justice systems. JLOs provide a single point of contact for workers within state and territory justice systems to coordinate support for NDIS participants in youth and adult justice systems;
 - improved provision of transport supports under the NDIS, with a commitment from the Australian Government to reimburse states and territories for their taxi subsidy schemes for NDIS participants from 1 January 2020 until 31 October 2021;

- inclusion of disability related health supports providing funding for self-care supports where the supports are a regular part of the participant’s daily life, and result from the participant’s disability;
- introduction of Health Liaison Officers (HLOs) by the NDIA across all states and territories to work with local health networks and key hospital staff to improve communication between hospitals and the NDIS in relation to hospital discharge;
- a national approach for the delivery of specialist school transport and personal care in schools under the NDIS;
- the implementation of Memorandums of Understanding between the Australian Government and states and territories to better support families with children who are unable to live in the family home due to their complex disability support needs;
- an improved national approach for child protection agencies to access NDIS plan information for children in statutory out-of-home care arrangements; and
- improved state and territory and NDIS respite supports for all NDIS participant children and their carers in statutory home-based care arrangements.

NDIS Quality and Safeguards measures

- 6.9 It is important to ensure people with disability, including people with autism, are able to access safe and quality services under the NDIS.
- 6.10 The NDIS Quality and Safeguards Commission (the NDIS Commission) was established as a Commonwealth statutory agency on 1 July 2018 for the purpose of furthering the objects and principles of the NDIS Act, and to uphold the rights of people with disability participating in the NDIS, as part of Australia’s commitment to the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), which Australia ratified in 2008. The NDIS Commission was established as an Australian Government statutory agency on 1 July 2018. The NDIS Commission is now operational in all jurisdictions except Western Australia, where it will commence operations from 1 December 2020.
- 6.11 The Commissioner of the NDIS Commission (the NDIS Commissioner), is the sole statutory officer with oversight and responsibility for all functions of the NDIS Commission. The Commonwealth Minister is responsible for administering the NDIS Act.
- 6.12 The NDIS Commission regulatory scheme is outlined in the NDIS Act. Section 181E of the NDIS Act outlines the NDIS Commissioner’s core functions. In addition to those core functions, the NDIS Commissioner has a registration and reportable incidents function pursuant to section 181F of the NDIS Act, a complaints function pursuant to section 181G of the NDIS Act, and behaviour support function pursuant to section 181H of the NDIS Act. It also outlines the NDIS Commission regulatory powers and approach to compliance and enforcement. It is an important feature of quality and safeguarding in the NDIS that all NDIS providers are regulated. NDIS providers are regulated through either or both:
- 6.12.1 the NDIS Code of Conduct, which is set out in the *National Disability Insurance Scheme (Code of Conduct) Rules 2018* and which applies to all NDIS providers and all persons employed or otherwise engaged by an NDIS provider; and
 - 6.12.2 the requirements to obtain and maintain registration as a registered NDIS provider, which apply to registered NDIS providers.

- 6.13 The establishment of the NDIS Commission gives effect to the Australian Government’s responsibilities under the nationally agreed NDIS Quality and Safeguarding Framework (the Framework). The Framework has foundations in the CRPD, the *Disability Services Act 1986* and the National Disability Strategy 2010–2020. It ensures that capability is built into the new market-based system, that the rights of people with disability are upheld, and that the benefits of the NDIS are realised.
- 6.14 The regulatory scheme is supported by the NDIS Rules, which articulate expected provider behaviour. There are also NDIS Guidelines, which identify indicators of effective application of the rules.
- 6.15 The NDIS (Restrictive Practices and Behaviour Support) Rules 2018 set out the conditions that apply to all registered NDIS providers in relation to behaviour support services and the use of restrictive practices, including the requirement to develop a behaviour support plan and report the use of restrictive practices to the NDIS Commission.
- 6.16 The NDIS Commission behaviour support function has regulatory oversight of restrictive practices and behaviour support, with an aim of reducing and ultimately eliminating the use of restrictive practices. Behaviour support under the NDIS Commission places a clear focus on person-centred interventions. States and territories retain responsibility for the authorisation of restrictive practices and are working towards greater national consistency in this area to support the national approach.

7 Supporting consistent, timely and best practice autism assessment and diagnosis

National Guideline for the Assessment and Diagnosis of Autism in Australia

- 7.1 The National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (the Guideline) was developed by the Autism Cooperative Research Centre (Autism CRC), with funding from the NDIA, and released on 16 October 2018. The then Minister for Families and Social Services, the Hon Paul Fletcher MP, and the Minister for Health, the Hon Greg Hunt MP, jointly launched the Guideline.
- 7.2 The process for developing the Guideline engaged hundreds of adults with autism, family members, clinicians and policy makers across Australia. As part of this process, the Autism CRC worked closely with the NDIA to ensure the Guideline aligns with the access and planning processes of the NDIS, in particular linking functional assessment and needs assessment as key steps in the process of diagnosis. Since its launch, the Guideline has been downloaded from the Autism CRC website over 14,000 times by clinicians, service providers and members of the public across more than 50 countries.
- 7.3 The Guideline was approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) under the *National Health and Medical Research Council Act 1992*. In granting approval, the NHMRC asserts that the Guideline has met its development standards, is of high quality, is evidence-based and has been developed with extensive consumer participation and public consultation. NHMRC approval is granted for a period of up to five years, and will expire in July 2023. Guidelines based on high quality evidence are key to establishing effective, high quality and safe health care practices.

- 7.4 DSS is working with Health, DESE, and the NDIA to drive further uptake of the Guideline, and ensure it is being applied consistently across professions, sectors and jurisdictions. This includes working with stakeholders to consider how best to support community understanding of the Guideline and use by relevant professions.
- 7.5 As an initial step, DSS has funded the Autism CRC \$194,000 (GST exclusive) to develop educational resources targeted at clinicians, service providers, people with autism and their families and carers. These resources will be published in a staged manner, with all products expected to be available before the end of 2020. The Autism CRC will supplement the grant amount with in-kind contributions.
- 7.6 Implementation is focused on supporting the professional uptake of the Guideline, so that people with autism can have access to timely high quality assessment and diagnosis and receive the right supports. DSS acknowledges that making diagnosis more consistent and accessible across Australia, and providing clarity for families seeking assessment, are important priorities for the autism sector. The Guideline aims to establish a minimum national standard for autism assessment and diagnosis. National implementation of the Guideline is likely to take some time to ensure it is understood, accepted and applied across various sectors.

8 Research into autism

Autism Co-operative Research Centre

- 8.1 In 2013, the Autism CRC received \$31 million in funding from the Australian Government, through the Cooperative Research Centres (CRC) Program, to support its establishment as the world's first national cooperative research centre focused on autism. The \$31 million in CRC grant funding is matched by over \$74 million of in-kind and cash contributions from the Autism CRC's 14 essential and 42 other participants.
- 8.2 The Autism CRC takes a whole-of-life approach to autism focusing on diagnosis, education and adult life. The objective of the Autism CRC is to undertake innovative research to directly improve the lifetime prospects of individuals with autism, provide guidance, support and direction for their families, and enable medical practitioners, educators, therapists, support workers and employers to work effectively with people with autism.
- 8.3 The Autism CRC also receives funding from:
 - other Australian Government and state and territory government grants (project specific);
 - cash contributions from participating universities and organisations; and
 - in-kind contributions from participating universities and organisations.
- 8.4 The Autism CRC has extensive networks throughout the autism field with researchers, service providers, clinicians and people with a lived experience of autism, across Australia and internationally. Utilising these formal networks, the Autism CRC provides government with access to robust, contemporary evidence about best practice.

National Health and Medical Research Council

- 8.5 The NHMRC is the Australian Government's main health and medical research funding body. The Australian Government allocates funds for health and medical research primarily through the Medical Research Endowment Account (MREA) and the Medical Research Future Fund (MRFF). NHMRC administers the MREA and some MRFF funds through grant programs.

- 8.6 The NHMRC recognises the importance of innovation in health and medical research, and launched a new grant program in 2018 that encourages greater creativity and innovation across the sector. The new grant program reflects the philosophy that health and medical research is best enabled by a diverse portfolio of schemes which support the most innovative research that is aiming to solve complex problems.
- 8.7 The NHMRC's research underpins advances in the health and wellbeing of individuals and communities, and plays a central role in supporting research and its translation across the full range of national health needs.
- 8.8 In relation to autism, since 2010 the NHMRC has provided \$33,826,231 in funding towards autism research. Examples of projects funded through NHMRC grant funding are provided at **Attachment D**.
- 8.9 The NHMRC does not generally determine the subject of research grant applications. Applications are investigator-initiated and therefore based on the expertise and research interests of those applying for funding. Research teams decide their research area and strategy prior to submitting an application to receive NHMRC funding. Grants are awarded based on competitive peer review with the best science and most significant research proposals funded based on the available funding allocation.

ASELCCs Research Agenda

- 8.10 From 2010, DSS has funded six ASELCCs to participate in the development and implementation of a data collection and research strategy. The ASELCCs are funded to collect clinical data, held in a centralised database, and to conduct and publish research to further understanding of best practice early intervention for children with autism and the efficacy of the ASELCC model for children and families.
- 8.11 By June 2018, the six ASELCCs and associated research institutions and partners had published 57 peer reviewed academic publications and five research reports contributing to national and international understanding of autism, early intervention and best practice.
- 8.12 ASELCC research findings have been summarised in the ASELCC Research Synthesis Report.⁵

Disability Research Strategy

- 8.13 In December 2019, the Disability Reform Council agreed to a disability research strategy with the Australian Government already committing:
- \$15 million for the development of the National Disability Data Asset; and
 - \$2.5 million to the Melbourne Disability Institute at the University of Melbourne to further develop a National Disability Research Partnership with other interested research and community organisations.
- 8.14 Over the next three years, the disability research strategy will seek to:
- establish a national framework and approach to collaboration on shared research priorities across government;
 - build capacity, capability and partnerships within the disability research community;
 - improve the quality, availability and utility of data to inform disability research; and
 - maximise the value of research in improving service models practicing and outcomes for people with disability in Australia.

Medical Research Future Fund

- 8.15 The MRFF, established under the *Medical Research Future Fund Act 2015* (MRFF Act), provides grants of financial assistance to support health and medical research and innovation to improve the health and wellbeing of Australians.
- 8.16 The MRFF operates as an endowment fund with the capital preserved in perpetuity. At maturity, the MRFF will reach \$20 billion. The MRFF provides a long-term sustainable source of funding for endeavours that aim to improve health outcomes, quality of life and health system sustainability.
- 8.17 The MRFF is in addition and complementary to research funding through the NHMRC.
- 8.18 MRFF investments are guided by the Australian Medical Research and Innovation Strategy 2016-2021 and related set of Australian Medical Research and Innovation Priorities 2018-2020 (the Priorities 2018-2020) developed by the independent and expert Australian Medical Research Advisory Board (AMRAB) following extensive national public consultation.
- 8.19 The Australian Government is required to consider the Priorities 2018-20 when making decisions on MRFF disbursements. The grant opportunities that result must be consistent with the AMRAB determined MRFF Funding Principles that highlight the need for funding research excellence through contestable grant processes and scientific peer review. Further information on the MRFF is available:
www.health.gov.au/campaigns/mrff?utm_source=health.gov.au&utm_medium=redirect&utm_campaign=digital_transformation&utm_content=mrff.
- 8.20 Currently, \$2.5 million over five years is being provided from the MRFF – Emerging Priorities and Consumer Driven Research Initiative from 2019-20 to understand the causes of autism.

9 Conclusion

- 9.1 The Australian Government funds a range of programs and research across early childhood, health, education and employment settings to improve the longer term outcomes of people with autism. While the role of the Government in funding autism specific supports has evolved over the past decade, particularly with the introduction of the NDIS, research and evidence gathered over that period has increased awareness of the diversity and need for effective inclusion of people with autism.
- 9.2 The Australian Government will continue to work with state and territory governments and the community to shape the future of policy and programs for people with autism, especially through the development of a new National Disability Strategy for beyond 2020. The new Strategy will be action oriented and aimed at creating a more inclusive society that enables all Australians with disability, including people with autism, to fulfil their potential as equal citizens.

¹ American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington: American Psychiatric Association.

² Australian Bureau of Statistics. (2018). Disability, Ageing and Carers, Australia: Summary of Findings, last updated 29 November 2019, available at:

www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=.

³ Ibid.

⁴ Department of Human Services administrative data.

⁵ Genders, S., & Katz, I. (2019). *ASELCC Research Synthesis Report*. Sydney: Social Policy Research Centre, UNSW Sydney, available at: <www.doi.org/10.26190/5d6867d737b32>.

Attachment A: Clients accessing HCWA Medicare Items

Source: Department of Health Data on service volume. On 1 July 2008, the Department of Health implemented new Medicare items for consultant paediatricians (item 135) or psychiatrists (item 289), on referral from a medical practitioner, to provide early diagnosis and treatment of autism or any other pervasive development disorder (PDD) for children aged under 13 years. The items are for assessment, diagnosis and creation of a treatment and management plan, including patient referral for MBS subsidised:

- allied health assessment services (items 8200-82030 - maximum 4 services); and
- allied health treatment services (items 82015-82035 - maximum 20 services).

Items 135 or 289 also provide a referral pathway for access to services provided through Childhood Autism Advisors by DSS.

Table 1: Item 135 service volume by time (row) and state (Cols) from Jan 2014 to April 2020

		State								Total
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services	
135 consultant paediatrician	2014	2,324	2,911	2,185	516	383	150	107	83	8,659
	2015	2,622	3,241	2,401	545	460	135	90	66	9,560
	2016	2,770	3,726	2,753	644	602	132	70	83	10,780
	2017	2,950	4,132	3,153	785	630	259	68	91	12,068
	2018	3,335	4,106	3,094	908	732	225	85	101	12,586
	2019	3,388	4,270	3,237	1,014	822	232	83	92	13,138
	YTD 2020	891	1,048	840	267	185	59	22	31	3,343
	Total	18,280	23,434	17,663	4,679	3,814	1,192	525	547	70,134

Table 2: Item 289 service volume by time (row) and state (Cols) from Jan 2014 to April 2020

Note: that MBS data does not record any services in Tasmania for the 2014-2020 period

		State							Total
		NSW	VIC	QLD	SA	WA	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services
289 psychiatrist	2014	102	42	129	10	3	0	1	287
	2015	99	68	169	15	29	0	0	380
	2016	75	68	160	26	9	1	1	340
	2017	75	54	210	41	9	3	0	392
	2018	93	53	158	22	6	0	0	332
	2019	102	51	115	30	7	3	1	309
	YTD 2020	33	22	32	2	3	0	0	92
	Total	579	358	973	146	66	7	3	2,132

Table 3: Allied health service volume of items 82000 – 82030 (assessment/diagnosis) by time (row) and state (Cols) from January 2014 to April 2020

Assistance with diagnosis/contribution to a treatment plan*

MBS items for allied health assessment and treatment of autism/PDD:

- 82000 psychologist
- 82005 speech pathologist
- 82010 occupational therapist
- 82030 audiologist, optometrist, orthoptist, physiotherapist

* Prerequisite MBS items: 110-131 (paediatrician) or 296-370 (psychiatrist).

		State								Total
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services	Services
82000 psychologist	2014	1,576	3,542	590	365	644	64	101	13	6,895
	2015	1,879	4,515	693	408	606	51	159	26	8,337
	2016	1,895	5,225	1,086	354	847	26	112	25	9,570
	2017	1,986	6,198	984	497	951	35	134	42	10,827
	2018	2,022	5,644	1,043	550	925	31	196	30	10,441
	2019	1,732	5,235	873	639	1,091	67	120	14	9,771
	YTD 2020	449	1,170	237	84	317	24	44	6	2,331
	Total	11,539	31,529	5,506	2,897	5,381	298	866	156	58,172
82005 speech pathologist	2014	386	1,889	345	299	448	13	0	10	3,390
	2015	519	2,131	289	327	496	15	3	25	3,805
	2016	827	2,204	356	352	705	7	0	20	4,471
	2017	803	2,336	383	508	778	19	0	22	4,849
	2018	647	2,083	522	609	820	23	6	41	4,751
	2019	607	1,979	424	553	856	7	0	41	4,467
	YTD 2020	137	359	99	59	259	6	0	11	930
	Total	3,926	12,981	2,418	2,707	4,362	90	9	170	26,663

		State								Total
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services	
82010 occupational therapist	2014	206	301	289	33	17	18	10	18	892
	2015	230	406	231	16	16	14	4	13	930
	2016	384	394	282	32	82	22	1	25	1,222
	2017	337	423	359	21	17	33	0	16	1,206
	2018	388	341	368	35	12	16	0	31	1,191
	2019	343	343	208	36	11	16	4	15	976
	YTD 2020	99	77	41	4	7	3	0	0	231
	Total	1,987	2,285	1,778	177	162	122	19	118	6,648
82030 audiologist, optometrist, orthoptist, physiotherapist	2014	12	28	50	9	1	1	2	0	103
	2015	339	29	71	7	8	2	0	0	456
	2016	331	29	72	2	75	0	1	1	511
	2017	203	139	151	5	31	0	1	0	530
	2018	138	165	74	1	25	0	0	0	403
	2019	181	219	67	0	28	0	0	0	495
	YTD 2020	55	56	14	0	0	0	0	0	125
	Total	1,259	665	499	24	168	3	4	1	2,623
2014		2,180	5,760	1,274	706	1,110	96	113	41	11,280
2015		2,967	7,081	1,284	758	1,126	82	166	64	13,528
2016		3,437	7,852	1,796	740	1,709	55	114	71	15,774
2017		3,329	9,096	1,877	1,031	1,777	87	135	80	17,412
2018		3,195	8,233	2,007	1,195	1,782	70	202	102	16,786
2019		2,863	7,776	1,572	1,228	1,986	90	124	70	15,709
YTD 2020		740	1,662	391	147	583	33	44	17	3,617
Total		18,711	47,460	10,201	5,805	10,073	513	898	445	94,106

Table 4: Allied health service volume of items 82015-82035 (treatment) by time (row) and state (Cols) from January 2014 to April 2020

Treatment services**

MBS items for allied health treatment of children with autism/PDD

- 82015 psychologist
- 82020 speech pathologist
- 82025 occupational therapist
- 82035 audiologist, optometrist, orthoptist, physiotherapist

** Prerequisite MBS items: 135 (paediatrician) or 289 (psychiatrist).

A **course of treatment** for the allied health treatment services consists of the number of allied health services stated on the child's referral, up to a maximum of 10 services. This enables the referring practitioner to consider a report from the allied health provider(s) about the services provided to the child, and the need for further treatment.

		State								Total
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services	Services
82015 psychologist	2014	1,072	1,874	1,120	385	173	54	38	17	4,733
	2015	908	2,050	948	189	194	65	58	2	4,414
	2016	911	1,951	1,069	229	165	56	14	24	4,419
	2017	961	2,317	1,181	294	280	97	1	5	5,136
	2018	1,065	3,116	1,800	306	394	60	6	26	6,773
	2019	1,001	2,473	1,558	357	370	67	1	18	5,845
	YTD 2020	200	360	212	60	73	11	11	2	929
	Total	6,118	14,141	7,888	1,820	1,649	410	129	94	32,249

		State								Total
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services	Services
82020 speech pathologist	2014	6,153	5,227	2,908	1,527	983	73	67	38	16,976
	2015	6,095	6,205	3,258	853	989	141	50	9	17,600
	2016	7,573	5,983	2,998	907	962	142	8	39	18,612
	2017	8,788	6,963	3,606	618	879	186	0	44	21,084
	2018	9,751	7,726	4,654	1,186	882	94	22	52	24,367
	2019	7,044	6,730	2,899	1,585	1,131	60	1	39	19,489
	YTD 2020	896	813	294	144	199	13	1	1	2,361
	Total	46,300	39,647	20,617	6,820	6,025	709	149	222	120,489
82025 occupational therapist	2014	2,583	1,479	2,046	658	294	40	79	54	7,233
	2015	2,509	1,727	1,990	292	228	69	42	25	6,882
	2016	3,713	2,155	2,127	584	177	84	21	17	8,878
	2017	4,605	2,993	3,019	583	197	112	0	66	11,575
	2018	5,274	4,200	4,006	1,433	366	82	37	125	15,523
	2019	3,714	3,608	2,918	1,405	667	59	13	17	12,401
	YTD 2020	533	518	418	187	145	8	6	0	1,815
	Total	22,931	16,680	16,524	5,142	2,074	454	198	304	64,307

		State								Total
		NSW	VIC	QLD	SA	WA	TAS	ACT	NT	
		Services	Services	Services	Services	Services	Services	Services	Services	Services
82035 audiologist, optometrist, orthoptist, physiotherapist	2014	156	149	178	165	37	0	8	0	693
	2015	199	151	135	80	43	0	22	0	630
	2016	554	176	152	23	97	12	0	0	1,014
	2017	416	278	207	41	124	36	37	0	1,139
	2018	111	198	382	39	100	3	10	0	843
	2019	112	91	229	48	63	0	0	0	543
	YTD 2020	21	2	44	0	9	0	0	0	76
	Total	1,569	1,045	1,327	396	473	51	77	0	4,938
2014		9,964	8,729	6,252	2,735	1,487	167	192	109	29,635
2015		9,711	10,133	6,331	1,414	1,454	275	172	36	29,526
2016		12,751	10,265	6,346	1,743	1,401	294	43	80	32,923
2017		14,770	12,551	8,013	1,536	1,480	431	38	115	38,934
2018		16,201	15,240	10,842	2,964	1,742	239	75	203	47,506
2019		11,871	12,902	7,604	3,395	2,231	186	15	74	38,278
YTD 2020		1,650	1,693	968	391	426	32	18	3	5,181
Total		76,918	71,513	46,356	14,178	10,221	1,624	553	620	221,983

Attachment B: Income Support Recipients with autism

Table 5: Income Support Recipients with a recorded medical condition of ‘Autistic Disorder’ – Recipients by Benefit Type
(Data as known at 27 September 2019)

Benefit Type	Number of Recipients
Disability Support Pension Only	16,921
Newstart Allowance	1,934
Youth Allowance (other)	1,515
Sickness Allowance	<5

Carer Payment Care Receivers	
Care Receiver Type	Number of Care Receivers
Not receiving an income support payment	27,091
Receiving Disability Support Pension	3,067

Data Descriptions

Includes the following recipients:

- Recipients of Newstart Allowance who are determined to be current (i.e. entitled to be paid) on the Centrelink payment system, and not in receipt of CDEP Participation Supplement or zero rate of payment, with an assessed Partial Capacity to Work.
- Recipients of Youth Allowance (other) who are determined to be current (i.e. entitled to be paid) on the Centrelink payment system, with an assessed Partial Capacity to Work (PCW). (Note: PCW refers to recipients with an assessed work capacity of under 30 hours per week).
- Recipients of Sickness Allowance who are determined to be current (i.e. entitled to be paid) on the Centrelink payment system, and not in receipt of zero rate of payment.
- Recipients of Disability Support Pension who are determined to be current (i.e. entitled to be paid) or suspended on the Centrelink payment system.
- Care receivers are identified as those persons receiving care who qualify their carer for Carer Payment.
- Note: Data includes those who have Asperger’s or autism reported in any of the medical condition fields (i.e. this does not reflect primary medical conditions, it reflects any medical condition and could be one of many).
- Note: in order to protect individuals' privacy, populations <5 are reported as '<5' and other data that would allow these populations to be derived are not provided 'np'.

Source: Services Australia administrative data. Report produced on 19 March 2020.

Attachment C: Policies and programs that support people with autism

The following table provides further detail on policies and programs, administered by DSS, Health or DESE that support the inclusion and participation of people with autism at all life stages.

Table 6: DSS, Health and DESE policies and programs

	Program / Policy	Description	Responsible department
C.1.	<i>Disability and early intervention supports</i>		
C.1.1	National Disability Insurance Scheme – Support for people with autism (including Early Childhood Early Intervention approach)	Refer paragraphs 2.5-2.8 and section 6 in main submission, and submission from the NDIA.	DSS / NDIA
C.1.2	Helping Children with Autism (HCWA) initiative – Individualised funding for early intervention	Refer paragraphs 3.4-3.8 in main submission.	DSS
C.1.3	HCWA block funded components <ul style="list-style-type: none"> • Autism Advisor Service • Early Days Workshops and National Coordinator • PlayConnect Playgroups • Raising Children Network – autism web content • Early Intervention Indigenous Liaison Officers 	Refer paragraph 3.9 in main submission.	DSS
C.2.	<i>Health and mental health</i> People with autism who have a mental illness or a mental condition are able to access health and mental health services available to the general population. This includes:		
C.2.1	Autism-specific Medicare Benefits Schedule (MBS) items (HCWA initiative)	Refer paragraphs 3.10-3.15 in main submission.	Health

	Program / Policy	Description	Responsible department
C.2.2	Mental Health Treatment MBS items	<p>General Practitioner (GP) Mental Health Treatment items (Items 2700 to 2717) support general practitioner early intervention, assessment and management of patients with mental disorders, including patient referral for MBS subsidised:</p> <ul style="list-style-type: none"> • psychiatry services (items 296 – 299, 319); and/or • psychological services (clinical psychologist items 80000 – 80021, allied mental health provider items 80100 - 80171). <p>Psychiatrists and consultant paediatricians may also directly refer patients to the above psychological services.</p>	Health
C.2.3	Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS	<p>This program is available to people who will benefit from a structured approach to treat mental disorders such as mild to moderate depression and anxiety where short-term evidence-based interventions are likely to be useful. These services can be accessed by visiting a GP who will assess whether a Mental Health Treatment Plan is appropriate.</p> <p>The number of sessions required depends on the diagnosis, duration and severity of the disorder. Patients can access Medicare rebates for up to 10 individual and 10 group allied mental health services per calendar year. Further information on the Better Access initiative is available at www.health.gov.au/mentalhealth-betteraccess.</p>	Health
C.2.4	Family Mental Health Support Services (FMHSS)	<p>A national non-clinical program to assist children and young people, aged up to 18 years, who are showing early signs of, or at risk of developing a mental illness.</p> <p>FMHSS provides counselling, family interventions, peer support, home-based support, education and skills development as well as community capacity building. FMHSS may assess the severity of a participant's mental health and/or their capacity to participate in the program, and will refer to appropriate specialist services as required.</p>	DSS

	Program / Policy	Description	Responsible department
C.2.5	Primary Health Networks (PHNs)	<p>The Australian Government also funds PHNs to lead mental health and suicide prevention service commissioning at a regional level. PHNs commission services within a person-centred stepped care approach that aims to improve outcomes for those with or at risk of mental illness and/or suicide, in partnership with local providers. The contact details for all PHNs can be obtained by referring to the website at www.health.gov.au/phn and clicking on the Map Locator.</p> <p>The Primary Care Division in the Department of Health is holding two forums to engage directly with people living with disability and intellectual disability, as well as their carers, peaks and academics. The aim is to understand the barriers to health care they experience, and the practical measures that may assist them. Specifically – these are:</p> <ul style="list-style-type: none"> • The Primary Health Care Reform Taskforce is holding a targeted consultation on disability focusing on primary care specific issues relating to disability to inform the National 10-year Primary Health Care Strategy. • The Department of Health will convene a second roundtable to continue development of the National Roadmap for Improving Health Services for People with Intellectual Disability (the National Roadmap). <p>A key priority of the National Roadmap will be a Primary Care Enhancement Program, to be developed through four lead PHNs over four years, with a view to national rollout across all PHNs.</p> <p>The forums were originally scheduled for April 2020 but have been postponed until later in 2020 following the COVID-19 outbreak. Note, the Department of Health has been working closely with the disability sector in response to COVID-19. The department has established an Advisory Committee and has held a number of roundtables with representatives from the disability sector. The department will continue to engage with the advisory committee on future primary health care reforms.</p>	Health

	Program / Policy	Description	Responsible department
C.2.6	National Roadmap for Improving Health Services for People with Intellectual Disability (the National Roadmap)	<p>While not all people with autism have an intellectual disability, implementation of the National Roadmap may benefit people with autism who also have intellectual disability. Implementation of the Roadmap may also serve as a platform for future health system policy changes that will benefit people with cognitive disability more broadly, including people with autism. The Department of Health will consult with the Australian Government on whether to expand the National Roadmap to include the health needs of people with autism or to develop policy in this area through a separate mechanism.</p> <p>On 2 August 2019, the Minister for Health, the Hon Greg Hunt MP, convened a roundtable of people with intellectual disability and their family members, academic experts and health care providers across a range of disciplines to discuss the challenges facing people with intellectual disability in accessing appropriate health care, and the opportunities to improve the system.</p> <p>The roundtable developed an outline of the National Roadmap, which identified a number of short, medium and long term initiatives under the following key elements:</p> <ul style="list-style-type: none"> • better models of care for people with intellectual disability and their families; • better support for health professionals to provide better care for people with intellectual disability; and • research, data and measurement to support continuing improvement. <p>A summary of the roundtable outcomes is available on the Department of Health's website at www1.health.gov.au/internet/main/publishing.nsf/Content/national-roadmap-for-improving-the-health-of-Australians-with-intellectual-disability (an outline of the National Roadmap is at Appendix B of the summary of roundtable outcomes).</p> <p>A second roundtable (which was to be held in April 2020) will be held later in 2020 following the COVID-19 pandemic, to further develop the National Roadmap.</p>	Health

	Program / Policy	Description	Responsible department
C.2.7	Professional Attendance	<p>GPs, consultant paediatricians and psychiatrists also provide services to individuals with autism or any other pervasive developmental disorder under MBS subsidised professional attendance items:</p> <ul style="list-style-type: none"> • GPs - items 3-4, 23-24, 36-37, 44, 47, 193, 195, 197, 199, 585, 594, 599, 2497-2559, 5000-5067 and 90020-90051; • Consultant paediatricians - items 110-131; and • Psychiatrists - items 296-370. 	Health
C.2.8	Chronic Disease Management	<p>GP management plan and team care arrangements items (721, 723, 729, 731 and 732) provide rebates to manage chronic or terminal medical conditions by preparing, coordinating, reviewing or contributing to chronic disease management (CDM) plans. They apply for a patient who suffers from at least one medical condition that has been present (or is likely to be present) for at least six months or is terminal.</p> <p>Eligible patients can claim a maximum of five allied health services in the period 1 January to 31 December (generally referred to as 'calendar year') (MBS items 10950-10970).</p> <p>Eligible allied health providers include - Aboriginal health workers or Aboriginal and Torres Strait Islander health practitioners, audiologists, chiropractors, diabetes educators, dietitians, exercise physiologists, mental health workers, occupational therapists, osteopaths, physiotherapists, podiatrists, psychologists and speech pathologists.</p>	Health

	Program / Policy	Description	Responsible department
C.2.9	National Safety and Quality Health Service Standards (NSQHS)	<p>A person with autism can experience difficulty with communication, behaviour and interacting with others. While there are a wide range of symptoms and abilities associated with autism, a person may also have a coexisting condition such as intellectual disability, have physical care needs and require assistance with self-care. Admission to hospital can be a distressing experience for the person and family and provide challenges for clinicians in understanding the person's presenting illness, communication, reducing distress, meeting the person's care needs and keeping the person safe. Safe and high quality care requires a person-centred approach where each individual's needs are understood and the person, person's family or support person are partners in care.</p> <p>The National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care in collaboration with the Australian Government, states and territories, private sector providers, clinical experts, patients and carers. The NSQHS Standards aim to protect the public from harm and to improve the quality of health service provision. The eight NSQHS Standards provide a nationally consistent statement about the level of care consumers can expect from health services. There are actions in the NSQHS Standards that support the provision of safe and high quality health care for people with autism. These include:</p> <ul style="list-style-type: none"> • At a governance and leadership level, the NSQHS Clinical Governance Standard requires health services to identify groups of patients who are at higher risk of harm and to incorporate information into planning and delivery of care. • The NSQHS Partnering with Consumers Standard encompasses actions to create a person-centred health system. • The NSQHS Comprehensive Care Standard aims to ensure that patients receive coordinated delivery of health care that is aligned with the patient's expressed goals of care, healthcare needs and is clinically appropriate and that any risks of harm are mitigated and managed. • The NSQHS Comprehensive Care Standard includes specific actions to address the needs of people with cognitive impairment and actions to minimise restrictive practices, such as physical and chemical restraint. • The NSQHS Communicating for Safety Standard requires a system to be in place to effectively communicate critical information, including from carers and families and at transition of care. 	Health

	Program / Policy	Description	Responsible department
C.3.	Education funding The Australian Government provides support for people with autism across their learning journey from childcare to early learning to school and for tertiary education.		
C.3.1	Positive Partnerships program to support school-age children on the autism spectrum (HCWA initiative)	Refer paragraphs 3.16-3.20 in main submission.	DESE
C.3.2	Support in early learning and childcare – Inclusion Support Program	Refer paragraphs 5.7-5.10 in main submission.	DESE
C.3.3	Nationally Consistent Collection of Data on School Students with Disability	Refer paragraphs 5.11 – 5.16 and 5.22 in main submission.	DESE
C.3.4	Student with disability loading	Refer paragraphs 5.17-5.24 in main submission.	DESE
C.3.5	Australian Student Wellbeing Framework	Refer paragraphs 5.25-5.26 in main submission.	DESE
C.3.6	Measures against bullying	Refer paragraph 5.27-5.28 in main submission.	DESE
C.3.7	Training and support for teachers	Refer paragraph 5.29-5.36 in main submission.	DESE
C.3.8	Funding and support for students in tertiary education	Refer paragraphs 5.37-5.39 in main submission.	DESE

	Program / Policy	Description	Responsible department
C.4.	Employment The Australian Government believes all Australians deserve to be included in the economic and social life of the community. One of the best ways to achieve this is through having a job. Work builds self-esteem and confidence, skills and life experience, and standing and identity in the community. It gives opportunities to fulfil personal goals and aspirations.		
C.4.1	jobActive	<p>The Australian Government’s ‘mainstream’ employment service jobActive helps job seekers, including people with autism, to stay engaged in the labour market, build their capability and increase their competitiveness so that they can take advantage of work opportunities as they arise.</p> <p>In jobActive, highly disadvantaged job seekers, including those with disability, tend to be in the higher streams of service, which are associated with greater funding and more support. Providers who deliver jobActive are required to have organisational strategies in place to provide individually tailored services to all job seekers, including those with disability such as autism. Providers also have access to the Employment Fund, which can be used to purchase goods and services to assist job seekers build experience and skills to get and retain a job.</p> <p>On 20 March 2019, the Government announced a New Employment Services Model to be implemented from July 2022. Key elements of the new model are being piloted in Adelaide South in South Australia and Mid North Coast in New South Wales from 1 July 2019 before being rolled out nationally. The new model aims to ensure that the needs of disadvantaged job seekers, including those with disability, are better addressed in the future.</p> <p>People with disability, including those with autism, also benefit from measures targeted at improving the employment prospects of youth, parents and mature age individuals. These include:</p> <ul style="list-style-type: none"> • the Transition to Work service, which provides intensive assistance to young people (aged 15 to 24) who have disengaged from work and study and are at risk of long-term welfare dependence. • Youth Jobs PaTH, to help young people gain the employability skills and real work experience they need to get a job. Those in Disability Employment Service (administered by DSS) can participate in the Internships element of PaTH (provided other eligibility requirements are met). • ParentsNext, a pre-employment program that assists eligible parents with young children to prepare for work by the time their children start school. • Career Transition Assistance, which provides guidance and training to help mature age job seekers (aged 45 and over) to be more competitive in their local jobs market. 	DESE

	Program / Policy	Description	Responsible department
C.4.2	JobAccess	<p>JobAccess is the national hub for workplace and employment information for people with disability, employers and service providers. Information and advice is provided at www.jobaccess.gov.au or by calling 1800 464 800.</p> <p>The JobAccess website provides tailored information to people with disability and employers, connecting them with free Australian Government disability employment supports, and includes content to help people with disability find long term employment. The JobAccess email and phone advice service answers general enquiries relating to disability employment matters.</p> <p>In making an enquiry to the JobAccess information and advice service, it is not mandatory for a disability type to be disclosed. In 2018-19, 4 per cent (about 120) of all new enquirers who disclosed a disability type (about 2,740) identified the relevant disability type as an individual with autism.</p>	DSS
C.4.3	Wage subsidies	<p>Wage subsidies encourage employers to hire, train and retain disadvantaged job seekers. They may be available to employers who hire people with autism participating in jobActive, Transition to Work and the intensive stream of ParentsNext, subject to meeting other eligibility criteria (in particular, the job seeker must also belong to one of the groups: mature age, parents, youth, long-term unemployed or Indigenous Australians).</p> <p>Entrepreneurship and self-employment is also supported, and encouraged, as an alternative pathway to employment. Support available to individuals who are interested in running their own business include:</p> <ul style="list-style-type: none"> • New Business Assistance with the New Enterprise Incentive Scheme (NEIS), which provides accredited small business training, personalised mentoring and support; • the SelfStart website, which provides information to support job seekers through the first stages of starting a business, from planning, validating the idea, finding local support, through to perfecting the pitch; and • help from Entrepreneurship Facilitators who can provide tailored mentoring and assistance with information on running a business. 	DESE

	Program / Policy	Description	Responsible department
C.4.4	Supported Wage System (SWS)	<p>The Supported Wage System (SWS) enables employers to pay a productivity-based wage to people whose work productivity is reduced as a result of disability. The SWS enables eligible people with disability to access a reliable process of productivity-based wage assessment to determine fair pay for fair work.</p> <p>The productivity of eligible participants is determined through workplace assessments undertaken by accredited assessors linked to National Panel of Assessors (NPA) panel members. This assessment process may be used in both open employment, where the relevant industrial award provides, and as of 1 July 2018 supported employment (employment in Australian Disability Enterprises (ADEs)), under the Supported Employment Services Award 2010 (SES Award)</p> <p>Of the approximately 5,700 SWS assessments undertaken in 2018-19, around 8 per cent of assessments were undertaken for employees who were identified as an individual with autism.</p>	DSS
C.4.5	Disability Employment Services (DES)	<p>The Disability Employment Services (DES) program helps individuals with a range of disabilities find and retain a job in the open job market. DES services are tailored to recognise all factors relevant to the individual, including the type and nature of their disability, work capacity, skills and experience, caring responsibilities, age and cultural and linguistic diversity.</p> <p>DES providers have expertise in connecting people with services and resources relevant to their individual needs, and would be able to assist with any autism-focused support available. At 29 February 2020, the DES program provided support to 10,862 participants with autism (including Aspergers).</p> <p>The Government consulted widely with the disability employment sector to determine how to better help people with disability to find employment, and a number of changes to the program took effect from 1 July 2018. These changes included giving participants greater choice and control over the support they receive from their preferred provider, and increasing the competition among DES providers to get better outcomes. The changes emphasised the need to better engage with employers, to ensure they understand the abilities of people with disability and the support available to help job seekers with disability integrate into their workforce.</p> <p>In particular, in 2018 the Government launched the Employ their Ability campaign to highlight the benefits of employing people with disability and to ensure employers are aware of the Government support and programs available to help them.</p>	DSS

	Program / Policy	Description	Responsible department
C.4.6	National Disability Employment Strategy	<p>Participation in the workforce is important for social inclusion and economic independence. Despite significant government investment, the unemployment rate for people with disability has remained the same for over 20 years (10.3 per cent), and is about double the rate for people without disability (4.6 per cent). The rate of unemployment for people with autism is even higher (34.1 per cent) and only 38 per cent of working age people with autism participate in the labour force.</p> <p>DSS is developing a strategy that will drive better employment rates for all working age people with disability, including people with autism, by reducing complexity in the current disability employment system, improving the effectiveness of programs and introducing new supports.</p> <p>It will aim to give people with disability access to the full suite of employment options, including self-employment, supported employment or mainstream corporate employment. The National Disability Employment Strategy will be informed by a review of the whole employment system, looking at what drives our jobseekers, employers and providers, as well as close engagement and consultation with the sector and relevant stakeholders.</p>	DSS
C.4.7	Disability Employment Assistance (DEA)	<p>The Disability Employment Assistance (DEA) program provides funding to Australian Disability Enterprises (ADEs), which are not-for-profit organisations that run commercial businesses, with the primary objective of employing people with disability, to assist them to provide on the job support to employees with moderate to severe disability so they can develop their capabilities and actively participate in community and economic life.</p> <p>Funding for supported employment is transitioning to the NDIS. To ensure that people with disability currently receiving on the job supports in ADEs through the DEA program are not disadvantaged in the transition to the NDIS, Continuity of Support will be available to those ADE employees ineligible for the NDIS.</p> <p>In the 2016-17 Financial Year, prior to the majority of supported employee transitioning to the NDIS, 12.6 per cent of all supported employees identified autism as their primary disability. As at 19 March 2020, 6.8 per cent of the remaining 1,458 supported employees in the DEA program identified autism as their primary disability.</p>	DSS

	Program / Policy	Description	Responsible department
C.4.8	Disability Support Pension (DSP)	<p>The Disability Support Pension (DSP) is designed to give people an adequate means of support if they have a permanent physical, intellectual or psychiatric impairment which attracts at least 20 points under the Tables for the assessment of work-related impairment for DSP (the Impairment Tables).</p> <p>When applying for DSP, the person must also be assessed as being unable to work for 15 or more hours per week, for at least the next two years, because of their impairment. The Impairment Tables contain 15 individual Tables that are designed to assess a person's loss of functional capacity that affects their ability to work. The Impairment Tables are specifically designed to assess work related impairment rather than whole person impairment. The tables are therefore function based rather than diagnosis based and describe functional activities, abilities, symptoms and limitations.</p> <p>Arrangements currently built into the DSP eligibility criteria seek to encourage and support people to re-enter and remain in the workforce. Once granted, all DSP recipients are able to engage in paid employment for less than 30 hours a week and still receive a part pension, subject to income testing. This assists people with disability, such as those with autism, to work where possible, while continuing to provide an essential safety net for people who are unable to fully support themselves.</p>	DSS
C.4.9	Carer Payment and Carer Allowance	<p>The Carer Payment and the Carer Allowance are fortnightly payments available to people who provide care to a person with disability or severe medical condition in a private home.</p> <ul style="list-style-type: none"> • The Carer Payment is income and assets tested and paid to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment. • The Carer Allowance is a supplementary payment for carers who provide a level of daily care and attention for people who need significant additional care. <p>Qualification for the Carer Payment requires the provision of constant care, considered to be roughly the equivalent of a normal working day. The care must be provided every day and assist with the activities of daily living – such as mobility, communication, hygiene and eating – or a range of cognitive and behavioural activities. Once a carer qualifies for the Carer Payment they are able to cease caring for up to 25 hours each week to participate in work or study without losing payment.</p> <p>To qualify for the Carer Allowance, carers who reside with the person they care for must provide care on a daily basis. Carers who live apart from the person they care for must provide at least 20 hours of personal care each week, with some of the 20 hours provided each day.</p>	DSS

	Program / Policy	Description	Responsible department
		<p>The Carer Payment and the Carer Allowance have two streams:</p> <ul style="list-style-type: none"> • Carer Payment (child) and Carer Allowance (child), for carers of children with disability or severe medical condition aged less than 16 years; and • Carer Payment (adult) and Carer Allowance (adult) for carers of people aged 16 and over. Qualification and assessment vary for each stream. <p>The Carer Allowance (child) has a two-step assessment process. The first step involves assessment of whether the child's disability or condition is on the List of Recognised Disabilities (the List). The List contains certain disabilities and medical conditions that are consistently severe enough to qualify the parent or carer for the allowance automatically. Where a child's condition is identified on the List, the carer will be granted the Carer Allowance. Autism spectrum disorder is contained on the List.</p> <p>If the child's disability or condition is not on the List, or if assessing the Carer Payment (child) then the Disability Care Load Assessment (DCLA) tool is used to determine eligibility. The DCLA considers the level of care required by the child or children with disability or medical condition, and the level of care provided by their carer.</p> <p>Qualification for the Carer Payment (adult) and the Carer Allowance (adult) is assessed by the Adult Disability Assessment Tool (ADAT), which consists of a questionnaire for the carer and a questionnaire for a treating health professional to complete, each resulting in a minimum qualifying score. The ADAT carer questionnaire considers the level of care needed by an adult because of his or her disability. It measures the amount of help required to undertake activities of daily living – such as communication, showering, toileting, grooming, dressing, feeding, mobility – and a range of cognitive and behavioural activities. This includes the need for prompting or supervision to undertake a task. Activities like banking, housework, shopping or cooking are not part of the assessment.</p>	

	Program / Policy	Description	Responsible department
C.4.10	Working age payments – Partial Capacity to Work	<p>People with autism may be eligible to receive the Newstart Allowance (NSA) and the Youth Allowance (other) (YA(o)) to support them to look for work or participate in approved activities that may increase their chances of finding a job.</p> <p>NSA and YA(o) recipients with a physical, intellectual or psychiatric impairment may be assessed as having a partial capacity to work if the impairment prevents them from working at least 30 hours per week at the relevant minimum wage or above, independently of a program of support, within the next two years.</p> <p>When setting a job seeker's mutual obligation requirements, employment services providers will consult with the job seeker and create a Job Plan that takes into account their individual circumstances, their assessed capacity to work and capacity to comply with the requirements.</p>	DSS
C.4.11	Social security concessions	<p>Income support recipients are generally automatically entitled to a Health Care Card.</p> <p>Pension recipients as well as some allowance recipients (including those receiving Newstart Allowance, Youth Allowance (job seeker) or Parenting Payment) who are assessed as having a partial capacity to work, are automatically entitled to a Pensioner Concession Card (PCC).</p> <p>People who are not receiving a social security payment may be entitled to a Low Income Health Care Card (LIC) if they meet a test of their average gross income in the eight weeks immediately before they make a claim for a card. As of 20 March 2020, the current income limit for a single person (no children) is \$570 per week (\$4,560 per eight-week period), while the current income limit for a couple, combined (no children) is \$984 per week (\$7,872 per eight-week period).</p> <p>Concession cardholders may access:</p> <ul style="list-style-type: none"> • medicines listed on the Pharmaceutical Benefits Scheme (PBS) at the concessional rate; • a lower PBS Safety Net threshold. After reaching the threshold, PCC holders are dispensed PBS prescriptions at no further charge for the remainder of that calendar year; • a lower Extended Medicare Safety Net threshold. After reaching the threshold, Medicare pays up to 80 per cent of any future out-of-pocket costs for out-of-hospital services for the remainder of the calendar year; and • concessions provided by state governments, local governments and private entities who provide these concessions at their discretion. 	DSS

	Program / Policy	Description	Responsible department
C.4.12	Individual Placement and Support (IPS)	<p>The Individual Placement and Support (IPS) model of employment assistance targets vulnerable young people with mental illness, aged up to 25, who are at risk of long-term welfare dependence because they disengage from education and employment. It is not required to have a diagnosis to be eligible for the program, so DSS does not have data on the rate of autism, or autism-related symptoms, amongst the participants.</p> <p>The IPS model integrates employment and vocational support with clinical mental health and non-vocational support, and focuses on the individual needs of people with mental illness who are seeking to remain in education and/or employment. Under this trial, professional employment specialists are fully integrated into 24 headspace services throughout Australia, working in tandem with clinical support and non-vocational assistance.</p> <p>The total cost of the trial over five years is about \$31 million. The Australian Government will make a decision about the future of the program closer to the end of the trial in June 2021, after the program data analysis has been finalised.</p>	DSS
C.4.13	Digital Work and Study Service	<p>The Digital Work and Study Service (the Service) provides education and employment support services through the headspace National Youth Mental Health Foundation. The Service is provided via a digital platform and it is integrated with clinical mental health services.</p> <p>Young people with mental illness, aged 15 to 25, are eligible participants. The Service works through web chat, video conferencing, email and phone – allowing young people to access the service wherever they are, and in a way they prefer. Young people can access various supports through the Service, including weekly assistance from trained specialists, webinars, mock interviews and linked support with employment service providers and industry professionals. It is available to all eligible young people but prioritises regional locations, Indigenous young people and early school leavers.</p> <p>It is not required to have a diagnosis to be eligible for the Service, so DSS does not have data on the rate of autism, or autism-related symptoms, amongst the participants. The Service is funded until June 2021 at \$1.2 million per year.</p> <p>The Australian Government will make a decision about the future of the Service closer to June 2021, after the Service data analysis has been finalised.</p>	DSS

	Program / Policy	Description	Responsible department
C.4.14	Employment Assistance Fund (EAF)	<p>The Employment Assistance (EAF) provides financial help to eligible people with disability and mental health conditions, and employers, to purchase work related modifications and services.</p> <p>The EAF can assist with the purchase of work related modifications and services like: the cost of making adjustments to a physical workplace; modifications to work vehicles; special equipment for the workplace; information and communication devices; Auslan interpreting and assistance for co-workers to learn sign language; specialist services for employees with specific learning disorders and mental health conditions and Disability Awareness Training.</p> <p>In 2018-19, 2,451 applications for assistance were approved under the EAF. Of these, 2 per cent (42 employers) identified the primary disability type of their employee as a person with autism.</p>	DSS
C.4.15	National Disability Recruitment Coordinator (NDRC)	<p>The National Disability Recruitment Coordinator (NDRC) provides support to employers, predominately larger employers, to increase their knowledge of the support available through Disability Employment Services (DES), helps employers implement disability employment practices, and provides disability awareness training for staff.</p> <p>The NDRC can work with any sized employer to create a job vacancy that is intended for a person with disability. In 2018-19, 130 alumni were engaged by the NDRC and 311 job vacancies were distributed. The NDRC works strategically with larger employers to teach them to develop and maintain sustainable disability recruitment and employment policies. This work is supported by a Memorandum of Understanding or Letter of Intent between the NDRC contracted entity and the employer, demonstrating an employer's commitment to increasing the number of people with disability employed within their organisation. In 2018-19, 38 signed partnerships were undertaken.</p> <p>The NDRC also delivers numerous Employer Seminars across Australia each year to help improve employer's knowledge and awareness of disability employment and the available government support including DES, the Employment Assistance Fund, Wage Subsidies and the Supported Wage System. In 2018-19, 663 employer engagement activities were undertaken by the NDRC.</p> <p>The NDRC works with DES providers to help create working relationships with employers. This helps DES providers develop an understanding of employers' business needs and culture, so they can match candidates with disability appropriately.</p>	DSS

	Program / Policy	Description	Responsible department
C.4.16	Collaborative Partnership to Improve Work Participation	<p>DESE is a member of the Collaborative Partnership to Improve Work Participation (the Collaborative Partnership), launched in March 2018.</p> <p>The Collaborative Partnership, established by Comcare, is a national effort by public, private and not-for-profit organisations to improve work participation for people with temporary or permanent physical or mental health conditions, which may impact their ability to work. One priority of the Collaborative Partnership is mobilising employers to improve their capacity to provide employment opportunities for people with physical and mental health conditions which impact upon their ability to work.</p>	DESE
C.4.17	National Centre for Vocational Education Research (NCVER)	Refer paragraph 5.40 in the main submission.	DESE
C.4.18	Registered training organisations (RTOs)	Refer paragraph 5.41 in the main submission.	DESE
C.4.19	Australian Skills Quality Authority (ASQA)	Refer to paragraph 5.42 in the main submission.	DESE

	Program / Policy	Description	Responsible department
C.4.20	<p>Australian Apprenticeships Incentives Program (AAIP)</p> <p>Disabled Australian Apprentice Wage Support (DAAWS)</p> <p>Off-the-job Tutorial, Mentor and Interpreter Assistance</p>	<p>The Australian Apprenticeships Incentives Program (AAIP) provides financial assistance to encourage and support Australian Apprenticeships for people with disabilities. Assistance includes the Disabled Australian Apprentice Wage Support (DAAWS) available to eligible employers, and the Off-the-job Tutorial, Mentor and Interpreter Assistance available to eligible Registered Training Organisations (RTO) (refer to paragraph 5.43 of the main submission).</p> <p>This assistance is intended to help an Australian apprentice with a disability, either directly, or indirectly through their employer, to reach their full potential as a skilled worker.</p> <p>Assistance is only available to support people with disabilities who are able to participate in open employment with a level of suitable training and support (refer to paragraph 5.43 of the main submission).</p> <p>DAAWS assistance is paid to an eligible employer at a rate of \$104.30 per week where they are paying an Australian apprentice a wage that is equal to or higher than this amount per week (refer to paragraph 5.43 of the main submission).</p> <p>Off-the-job Tutorial, Mentor and Interpreter Assistance is available to the RTO where they provide off-the-job assistance to the Australian apprentice. The assistance must be in addition to the standard off-the-job training and is paid to the RTO based on the actual time spent providing individualised assistance (refer to paragraph 5.43 of the main submission).</p>	DESE

	Program / Policy	Description	Responsible department
C.5.	<i>Social inclusion</i> The Australian Government provides targeted services and initiatives to build stronger and more resilient individuals, families and communities. This includes activities to increase the participation of vulnerable and disadvantaged individuals and families within their communities and enhance their life-time wellbeing and sense of community belonging.		
C.5.1	Strong and Resilient Communities (SARC) Mutual Understanding, Support, Tolerance, Engagement and Respect (MUSTER)	<p>Strong and Resilient Communities (SARC) and Mutual Understanding, Support, Tolerance, Engagement and Respect (MUSTER) grants aim to build strong, resilient, cohesive and harmonious communities to ensure that individuals, families and communities have the opportunity to thrive, be free from intolerance and discrimination, and have the capacity to respond to emerging needs and challenges.</p> <p>At March 2020, two activities are funded under SARC that assist people with autism:</p> <ul style="list-style-type: none"> • STEPS Group Australia are funded \$487,500 over three and a quarter years to work with children and youth with autism and their parents to improve well-being, strengthen family relationships and resilience, increase engagement in schooling, and minimise isolation and marginalisation while enhancing a sense of belonging to community. • Autism Community Network are funded \$465,464 over three years, with funding ending 30 June 2021, to increase social participation of carers as well as adults and children with autism to help increase their wellbeing and sense of belonging. <p>Under the MUSTER grant program:</p> <ul style="list-style-type: none"> • Spectrum Journeys will receive \$103,740 over two financial years, ending on 30 June 2020, to deliver a workshops and events for parents, carers and educators of children with autism to build capability and connections. • Waves and the Spectrum will receive \$160,000 over two financial years to 30 June 2021, to run therapeutic surf days in NSW and Qld for young people with autism and their families. 	DSS
C.5.2	Volunteer Grants	<p>Volunteer Grants provides grants of between \$1,000 and \$5,000 to help not-for-profit organisations to support the volunteers who help disadvantaged Australian communities and encourage inclusion of vulnerable people in community life.</p> <p>In the 2018 Volunteer Grants round, nine organisations that support people with autism received grants totalling \$28,490.</p>	DSS

	Program / Policy	Description	Responsible department
C.5.3	Sing and Grow Australia (Qld)	The Playgroups Association of Queensland delivers the Sing and Grow evidence-based international music therapy project for young children aged up to five years, and their families, who present with complex needs. The project focuses on strengthening family relationships, building capacity in parents to support their children's development in the early years of life, and encouraging the use of music within communities. The Playgroups Association of Queensland collaborates with existing family support agencies to deliver comprehensive music therapy services within an integrated early intervention and prevention framework.	DSS
C.5.4	My Time	My Time is a national program of facilitated peer support groups for parents eligible for the Carer (Child) Allowance. MyTime is delivered in 198 locations across Australia.	DSS
C.5.5	National Plan to Reduce Violence against Women and Their Children 2010-2022	<p>Initiatives under the National Plan to Reduce Violence against Women and Their Children 2010-2022 to support women with disability:</p> <ul style="list-style-type: none"> • Through the Third Action Plan, the Sunny application was developed by 1800RESPECT to support women with disability (including autism) to understand violence, know their rights, and seek assistance, if required. The Sunny application includes easy English definitions of violence that guide users through scenarios to help them recognise abuse. The application was designed in partnership with an expert advisory group, which included women with disability. Since its launch in November 2018, more than 1,900 users have downloaded the application. 1800RESPECT launched the 'That is Violence' campaign in 2019 to help encourage women with disability to download the Sunny application or reach out to 1800RESPECT for support. Following the campaign there was an increase in 1800RESPECT contacts disclosing they had a disability. • Under the Third Action Plan, Lifeline Australia is funded \$26.2 million to develop workforce training for the disability sector as part of the DV-alert program. This includes a two-day accredited face-to-face workshop and an accredited eLearning course to build the knowledge and capacity of community frontline workers who support people with disability. The training assists frontline workers to recognise, respond to, and effectively refer women with disability and their children who are experiencing or are at risk of domestic and family violence, to support services. More than 320 participants completed the accredited face-to-face DV-alert workshop between the 2017-18 and 2018-19 financial years, and more than 120 participants completed the eLearning between 1 January and 30 June 2019. • Through the Fourth Action Plan, the Australian Government has invested \$1.5 million for the Office of the eSafety Commissioner to assist women with disability (including autism) to protect themselves online, and to identify and report technology facilitated abuse. 	DSS

	Program / Policy	Description	Responsible department
C.6.	<i>Advocacy supports</i> Since 1987, the Australian Government has funded disability advocacy to ensure the rights of people with disability are protected and promoted, consistent with Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities. Where appropriate, advocacy organisations provide the necessary support, tools and information to assist an individual to self-advocate in relation to a range of issues they may be experiencing. The Australian Government and states and territories, with the exception of South Australia, currently fund disability advocacy. In 2019-20, the Australian Government commitment to disability advocacy is close to \$46 million. This commitment supports the following programs.		
C.6.1	National Disability Advocacy Program (NDAP)	<p>The National Disability Advocacy Program (NDAP) provides people with disability, including people with autism, access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation. Disability advocacy is acting, speaking or writing to promote, protect and defend the human rights of people with disability. In 2019-20, NDAP funding is \$20.8 million.</p> <p>The NDAP promotes the social inclusion and participation of people with disability within the economy and community by providing access to the following types of advocacy:</p> <ul style="list-style-type: none"> • Citizen advocacy: matches people with disability with volunteers. • Family advocacy: helps parents and family members advocate on behalf of the person with disability for a particular issue. • Individual advocacy: upholds the rights of individual people with disability by working on discrimination, abuse and neglect. • Legal advocacy: upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect. • Self advocacy: supports people with disability to advocate for themselves, or as a group. • Systemic advocacy: seeks to remove barriers and address discrimination to ensure the rights of people with disability. <p>All persons with disability, including those with autism, may access services funded through NDAP.</p> <p>Up until 2016-17, 12.4 per cent of people accessing assistance through the NDAP identified as having autism. With the introduction of new reporting requirements in 2017-18, providers are no longer required to report to the same level of detail, as such, autism is now captured within a broader ‘psychiatric’ category that includes a number of other conditions and not solely limited to autism. In 2018-19, the psychiatric category represented 22.9 per cent of clients accessing disability advocacy services.</p>	DSS

	Program / Policy	Description	Responsible department
C.6.2	NDIS Appeals Program	<p>The NDIS Appeals Program has been set up to ensure that all people with disability, and other people affected by reviewable decisions of the NDIA, have access to support when seeking review of those decisions in the Administrative Appeals Tribunal (AAT). In 2019-20, NDIS Appeals Program funding is \$10.7 million.</p> <p>There are two types of supports available via the NDIS Appeals Program:</p> <ul style="list-style-type: none"> • access to a skilled disability advocate who acts as a support person; and • access to funding for legal services in some cases. <p>Parents of children with autism are among those who access the supports available through NDIS Appeals program.</p>	DSS

	Program / Policy	Description	Responsible department
C.6.3	Disability Representative Organisation Program	<p>The Disability Representative Organisation (DRO) program provides systemic advocacy and representation for Australians with disability, including people with autism. The program provides the capacity for all people, and their representative organisations, to have their views communicated to the Australian Government, regardless of type of disability, gender, cultural background, age or membership.</p> <p>The disability peak bodies are currently funded over \$2 million per year.</p> <p>The funding is to enable organisations to provide systemic advocacy for Australians with disability to:</p> <ul style="list-style-type: none"> • promote an understanding of the lives of people with disability • promote and protect the rights and dignity of people with disability • support service providers in delivering services to people with disability • foster support for the participation of people with disability in all aspects of community life. <p>These peak bodies provide advice to the Australian Government on breaking down barriers and improving social and economic participation, and engage with a range of ministers and portfolios.</p> <p>Autism Aspergers Advocacy Australia (A4) is a member of the Australia Federation of Disability Organisations (AFDO) which is funded by the DRO program. A4 supports and represents their membership base by providing advice to the Australian Government on breaking down barriers and improving social and economic participation of people with autism and Aspergers.</p> <p>A4 attended a one-day workshop for the DROs at DSS. These workshops provided one mechanism for a voice to government for people with disability. A4 is also funded to provide systemic advocacy to assist people with autism to engage with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission).</p>	DSS

	Program / Policy	Description	Responsible department
C.6.4	Additional advocacy supports for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability	<p>To supplement existing disability advocacy programs supported by DSS, additional funding has been provided to extend the work of individual advocacy providers under National Disability Advocacy Program (see C.6.1) and systemic advocacy under the Disability Representative Organisation funding program (see C.6.3). This includes an additional \$50,000 per annum (for three years) for Autism Aspergers Advocacy Australia (A4), funded through AFDO.</p> <p>Additionally, the First Peoples Disability Network has been funded to increase access to culturally appropriate advocacy support to allow Indigenous people with disability to engage with the Disability Royal Commission. Total support for the Indigenous approach to Disability Royal Commission Advocacy is \$6 million over three years.</p> <p>All people with disability, including those with autism, may access services funded through the Disability Royal Commission advocacy support program.</p> <p>Over \$33 million has been allocated to support Disability Royal Commission advocacy.</p>	DSS

Attachment D: National Health and Medical Research Council funding for autism research

Table 7: Examples of NHMRC grants for autism research

Application Year	Grant ID	Chief Investigator Name	Title	Administering Institution	State	Grant Amount	Summary
2020	GNT1194358	A/Pr Chee Ooi	Closing the Clinical Translation Gap of the Gut Microbiome in Chronic Diseases	University of New South Wales	NSW	\$1,337,350	The gut microbiota is important for human health and disease but knowledge transfer to clinical practice is lacking. This proposal will investigate how diet and gut microbiota changes connect with physical symptoms, mental health and behavioural issues in chronic diseases, using cystic fibrosis and autism spectrum disorder as models of disease. Improved understanding can improve management, assist in developing targeted therapies and is key to providing real-world solutions to improve outcomes.
2020	GNT1196855	Prof Geoffrey Goodhill	Mapping neurodevelopmental disorders in a zebrafish model	University of Queensland	QLD	\$2,760,520	The way in which the brain develops differently in neurodevelopmental disorders, such as autism, is hard to reveal in humans but can be addressed in a zebrafish model. Using cutting-edge imaging and computational techniques, this project will investigate how neural representations of the world develop differently between normal zebrafish and zebrafish mutant for a gene that causes autism. This will provide new insights into the mechanisms of altered circuit development in autism.

Application Year	Grant ID	Chief Investigator Name	Title	Administering Institution	State	Grant Amount	Summary
2019	GNT1173896	Prof Andrew Whitehouse	Improving clinical outcomes for children with autism spectrum disorder: A research program spanning basic, clinical and implementation science.	University of Western Australia	WA	\$3,146,472	Autism is a lifelong developmental condition that is diagnosed in 2 per cent of Australians. This research program aims to significantly advance knowledge in three areas that are key to improving long-term wellbeing in children with autism. By combining expertise from a range of fields, the program will increase our understanding of why some children develop autism, which therapies are most effective in reducing disability and how we can incorporate scientific findings into clinical practice.
2019	GNT1176077	Prof Peter Anderson	Optimising Neurodevelopmental Outcomes in 'At-Risk' Infants	Monash University	VIC	\$2,259,222	This research focusses of the thousands of infants born each year who are at risk for neurodevelopmental problems including intellectual disability, attention deficit/hyperactivity disorder and autism. The objective is to learn more about factors that occur during pregnancy, at birth, or shortly after birth contributing to neurodevelopmental problems, and to develop new interventions to reduce these problems. Findings will have the potential to transform treatment services for high risk infants.

Application Year	Grant ID	Chief Investigator Name	Title	Administering Institution	State	Grant Amount	Summary
2018	GNT1170724	Prof Anne-Louise Ponsonby	Novel Testing Strategies for Endocrine Disruptors in the Context of Developmental NeuroToxicity: Australian Component	University of Melbourne	VIC	\$498,150	Modern children are exposed to many man-made chemicals. An Australian birth cohort study will investigate how common exposure in utero really is and whether higher exposure is linked to attention deficit disorder and autism spectrum disorder. This project is the Australian contribution to an international effort to understand potentially harmful chemical effects on the developing child's brain and to improve the testing and regulation of chemicals, particularly in early life.
2018	GNT1171206	A/Pr Helen Leonard	A multicentre double-blind placebo-controlled randomised trial of SerTRaline for AnxieTy in adults with Autism (STRATA)-Australian component	University of Western Australia	WA	\$557,029	Anxiety is a debilitating symptom affecting many people with autism. However, it is not known how effective and how well tolerated are the medications, which are used to treat anxiety in the general population, when prescribed to people with autism. To answer this question, a proposed clinical trial of one anxiety medication (sertraline) across five sites in two countries. Over 300 adults with autism will be recruited, and half will receive the active drug and half a placebo or dummy medication.

Attachment E: Terms of Reference Matrix

Table 8: Terms of reference matters addressed by this submission, for the Committee’s reference

Priority area (Terms of Reference)	Program / Policy	Reference in submission	Responsible department
a. Current approaches and barriers to consistent, timely and best practice autism diagnosis.	National Guideline for Assessment and Diagnosis of Autism in Australia	See paragraphs 7.1-7.6	DSS
	Medicare Benefits Schedule Review Taskforce	See paragraphs 4.15-4.17	Health
b. The prevalence of autism in Australia.	Relevant data noted at paragraphs 1.2-1.3		
	Social security data (income support)	See Attachment B	DSS
c. Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services.	See paragraph 1.3		
d. International best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity.	National Guideline for Assessment and Diagnosis of Autism in Australia	<p>Information on the Guideline is provided at paragraphs 7.1-7.6 in the main submission. Of particular relevance:</p> <ul style="list-style-type: none"> • The process for developing the Guideline engaged hundreds of adults with autism, family members, clinicians and policy makers across Australia. • The Guideline was endorsed by the National Medical and Health Research Council, asserting that the Guideline has met its development standards, is of high quality, is evidence-based and has been developed with extensive consumer participation and public consultation. • The Autism Cooperative Research Centre conducted a rigorous process to develop the Guideline, including a series of literature reviews and community consultations. This included review and analysis of the international guidelines and best practice standards. 	DSS
e. The demand for and adequacy of Australian, state and local government services to meet the needs of autistic people at all life stages.	<p><i>This submission provides a comprehensive snapshot of the Australian Government’s policy framework and current funding, programs and policies to support people with autism, their carers, family and friends.</i></p> <p>See also priority area (k) below.</p>		

Priority area (Terms of Reference)	Program / Policy	Reference in submission	Responsible department
f. The interaction between services provided by the Australian, state and territory and local governments, including: <ul style="list-style-type: none"> i. health and mental health; ii. education; iii. employment; iv. justice; and v. housing. 	See paragraphs 1.4-1.7 and 1.10-1.11 <i>More detail on Australian Government funding, programs and policies in the areas of health and mental health, education and employment (including interaction with state government services, where relevant) is provided in the submission.</i> See also priority area (k) below.		
g. The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of people with autism.	<i>Many Australian Government programs and policies focus on supporting people with autism during the key life stage transitions, as outlined out in this submission. For example:</i>		
	Helping Children with Autism (HCWA) individualised funding	The early intervention approach delivered through the HCWA individualised funding (paragraphs 3.4-3.8) can foster significant improvement in life outcomes for the child and family, improve the child's ability to transition into a mainstream education setting and provide parents/carers with tools to build their own capacity to meet their child's needs.	DSS
	Autism Specific Early Learning and Care Centres (ASELCCs)	The ASELCCs (paragraphs 4.1-4.5) support children with transitions into further educational and therapeutic settings so that they can reach their full potential, as well as providing parents with the opportunity to participate more fully in education, employment and the community.	DSS
	National Disability Coordination Officer Program	About \$4.4 million in funding is provided annually to the National Disability Coordination Officer Program (paragraph 5.39) to assist people with disability to transition from school to tertiary education and subsequent employment.	DESE
h. The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for people with autism, including: <ul style="list-style-type: none"> i. autism understanding within the NDIS; 	Support for people with autism through the NDIS, including:	See section 6 of main submission	DSS / NDIA
	Data on NDIS participants with autism	See paragraphs 6.5 and 6.17-6.19	NDIA
	Early Childhood Early Intervention approach	See paragraphs 6.11-6.19	NDIA

Priority area (Terms of Reference)	Program / Policy	Reference in submission	Responsible department
ii. the utility of the Early Childhood Early Intervention Pathway for children with autism; iii. the ability of the NDIS to support people with autism with complex needs, including those transitioning from prison settings; and iv. the adequacy and appropriateness of supports to empower people with autism to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services.	NDIS mainstream interfaces (including justice, health and child protection)	See paragraphs 6.20-6.23	DSS / NDIA
	NDIS Quality and Safeguards measures	See paragraphs 6.24-6.31	DSS / NDIS Quality and Safeguards Commission
i. The development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy.	National Disability Strategy 2010-2020 and development of a new National Disability Strategy	See paragraphs 2.15-2.15.2 and paragraph 9.2	DSS
	Reimagine Early Childhood: A National Action Plan to Improve Outcomes for Children with Disability and Developmental Delay	See paragraph 2.15.3	DSS
j. The adequacy of funding for research into autism.	Autism Cooperative Research Centre	See paragraphs 8.1-8.4	DSS / DISER
	National Health and Medical Research Council	See paragraphs 8.5-8.9 and Attachment D	Health
	ASELCCs Research Agenda	See paragraphs 8.10-8.12	DSS
	Disability Research Strategy	See paragraphs 8.13-8.14	DSS
	Medical Research Futures Fund	See paragraphs 8.15-8.20	Health
k. The social inclusion and participation of people with autism within the economy and community.	<i>Australia's social support system is designed to improve people's employment and social outcomes. People with autism and families and carers are able to access programs and payments to support their economic and social participation, including: (see also paragraph 2.3).</i>		
	Health and mental health	For a full list of relevant programs and policies, see Attachment C: Table 6 at C.2	Refer Attachment C

Priority area (Terms of Reference)	Program / Policy	Reference in submission	Responsible department
	Education	See section 5 for a full list of relevant programs and policies, see Attachment C: Table 6 at C.3	Refer Attachment C
	Employment	For a full list of relevant programs and policies, see Attachment C: Table 6 at C.4	Refer Attachment C
	Social inclusion	For a full list of relevant programs and policies, see Attachment C: Table 6 at C.5	Refer Attachment C
l. The capacity and sustainability of advocacy, self-advocacy and self-determination supports for people with autism, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities.	For detail on Australian Government funding for disability advocacy supports, see Attachment C: Table 6 at C.6		DSS
m. Any bill that relates to matters within the scope of this inquiry that is referred to this committee.	N/A		
n. Any other related matters.	National Roadmap for Improving Health Services for People with Intellectual Disability	See Attachment C: Table 6 at C.26	
	<i>Support for people with autism from Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse backgrounds, including:</i>		
	HCWA Early Days Workshops (including tailored workshops delivered to Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities)	See paragraphs 3.9.2 and 3.9.3	DSS
	HCWA Early Intervention Indigenous Liaison Officers	See paragraph 3.9.6	DSS
	Positive Partnerships (HCWA initiative) – tailored resources and engagement with Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities	See paragraphs 3.16-3.20	DESE