

# Submission to the Senate Select Committee on Autism

July 2020

# Contents

<b>1</b>	<b>Introduction .....</b>	<b>4</b>
1.1	The role of the National Disability Insurance Scheme .....	4
1.2	NDIS participants with autism .....	4
1.3	Improving understanding of autism within the NDIA .....	5
<b>2</b>	<b>Autism in Australia .....</b>	<b>6</b>
2.1	Prevalence of autism in Australia.....	6
2.2	Females with autism in Australia .....	8
2.3	Autism diagnostic practices in Australia .....	9
2.4	Early detection and intervention .....	10
<b>3</b>	<b>Autism and the NDIS .....</b>	<b>10</b>
3.1	Assessing individual need .....	10
3.2	Early Childhood Early Intervention (ECEI) approach and children with autism .....	11
3.3	Seven to 17 year old NDIS participants with autism .....	12
3.4	Adult NDIS participants with autism .....	13
3.5	Information, Linkages and Capacity (ILC) building .....	14
3.6	Key challenges for the NDIS now and into the future .....	14
<b>4</b>	<b>Improving the NDIA's responsiveness to the needs of people with autism.....</b>	<b>15</b>
4.1	Overview .....	15
4.2	Consulting with key autism stakeholders via the Autism Advisory Group (AAG).....	15
4.3	Other consultation approaches .....	16
4.4	Pathway improvements .....	16
4.5	Improved NDIA organisational and staff capabilities .....	17
<b>5</b>	<b>The NDIA's contribution to improving outcomes for people with autism in Australia .....</b>	<b>18</b>
5.1	Person centred -planning .....	18
5.2	Introduction of reasonable and necessary guidance on best practice in behaviour support .....	18

<b>5.3</b>	<b>Clarity and consistency of reasonable and necessary decisions guidance for early intervention.....</b>	<b>19</b>
<b>5.4</b>	<b>Early Childhood Early Intervention (ECEI) Approach implementation reset .....</b>	<b>19</b>
<b>5.5</b>	<b>Improving linkages and referrals for people who are ineligible for NDIS .....</b>	<b>20</b>
<b>5.6</b>	<b>COVID-19 research project.....</b>	<b>20</b>
	<b>Appendix A - Supports provided under the NDIS .....</b>	<b>21</b>
<b>5.7</b>	<b>Overview .....</b>	<b>21</b>
<b>5.8</b>	<b>NDIS funded supports and interface with mainstream supports.....</b>	<b>21</b>
<b>5.9</b>	<b>How is the decision made to include supports? .....</b>	<b>22</b>
<b>6</b>	<b>Appendix B - Plan Development and Review .....</b>	<b>25</b>
<b>7</b>	<b>Appendix C - Information Linkages and Capacity Building.....</b>	<b>28</b>

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# 1 Introduction

The National Disability Insurance Agency (NDIA) welcomes the establishment of the Select Committee on Autism (Committee) and recognises its importance of looking into a wide range of issues relating to the services, support and life outcomes for people with autism<sup>1</sup> – including diagnosis, education, health (including mental health), employment, justice and rights, and housing.

This submission provides information on autism prevalence, diagnosis, National Disability Insurance Scheme (NDIS) supports for participants with autism, and improvements the NDIA is making to the NDIS to improve outcomes for people with autism.

## 1.1 The role of the National Disability Insurance Scheme

The NDIS is a joint initiative of the Commonwealth, state and territory governments. As such, all Australians are important stakeholders in the NDIS. The NDIS is founded on an insurance approach of early investment, with the objective of building individual capacity in participants (NDIS participants) to live independent lives in inclusive communities, making it a scheme for all Australians. Australians share the risk and the cost of disability services and supports. This insurance approach is underpinned by three principles:

- (i) focus on lifetime value for NDIS participants;
- (ii) invest in research and encourage innovation; and
- (iii) Support the development of community capability and social capital.

The NDIS is the first national approach to the provision of disability supports in Australia. The move from individual state systems to the NDIS is intended to provide participants with access to the same approach to 'reasonable and necessary' supports regardless of where they live. The purpose of the NDIA is to increase the capacity of individuals with a significant and permanent disability to be more independent, and engage more socially and economically, at the same time as delivering a financially sustainable NDIS that inspires community and stakeholder confidence.

The NDIS has an emphasis on individual choice and control and NDIS participants control the supports they receive, when they receive them, and who provides them. Every NDIS participant has an individual plan that lists their goals and the funding they have received. NDIS participants are given a plan of supports developed and tailored to their individual needs. A plan could include informal supports that a person receives through family, friends, mainstream or other community services. The NDIS provides reasonable and necessary funding to people with a permanent and significant disability to access the supports and services they need to live and enjoy their life.

As every participant has different goals, which can include objectives like getting and keeping a job, making friends or participating in a local community activity, the types of supports funded from plans can differ between participants. The specialist disability supports funded by the NDIS complement the mainstream services that all Governments provide, such as health, education, corrections, housing, justice, transport and safety. More information about the type of supports funded within NDIS plans is included at Appendix A.

Not all people with disability will become NDIS participants. Only those who meet the access criteria will become a participant and receive an individualised plan. However, the NDIS will continue to provide people with disability, their families and carers, support through its Partners in the Community, known as Local Area Coordinator and Early Childhood Early Intervention that assists people with disabilities in the mainstream community.

## 1.2 NDIS participants with autism

As of 30 June 2020, there are approximately 382,631 participants in the NDIS. Of these, 119,750 (31%) have a primary diagnosis of autism. The NDIA uses insurance principles in its design and delivery of the NDIS. This includes encouraging cost effective early interventions to minimise long-

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<sup>1</sup> Autism is used throughout this document and is inclusive of Autism Spectrum Disorder, Autism and Asperger's Syndrome

term costs to the NDIS and improve outcomes for participants. As such, the NDIA expects many people with autism would enter the NDIS in childhood for early intervention supports, who may not need the NDIS in later life.

The NDIS released the Outcomes for participants with autism in June 2018. That report found that while outcomes for participants with autism are worse in many respects than those for participants with other disabilities, participant perception of whether the NDIS has helped show participants with autism are more likely to report the NDIS has helped them than participants with other disabilities, except in the education domain. The report also found that parents of children aged 0-6 with a primary diagnosis of autism were more likely to report their children had been welcomed or actively included in community activities than parents of children with other disabilities. This report is available at <https://data.ndis.gov.au/reports-and-analyses/outcomes-participants-autism-spectrum-disorder>.

### **1.3 Improving understanding of autism within the NDIA**

The NDIA recognises that people with autism have benefit from evidence-based, effective early intervention, and may have differing support needs in their adult years. Accordingly, the NDIA has implemented improvements to increase scheme understanding and awareness as a response to state government and community feedback. The formation of an Autism Advisory Group (AAG) in 2018 by the NDIA identified participants with autism as a cohort requiring further policy and practice adjustments to improve the scheme's responsiveness to their particular needs. A range of improvements have been implemented over the past two years and this work is ongoing.

The NDIA is currently planning improvements in the early intervention and school age years for participants with autism. In mid-2020, the NDIA with the guidance of the AAG developed a project to improve the NDIS response to intensive behaviour intervention programs. Working with the Autism Co-operative Research Centre (Autism CRC), the NDIA is collaborating with key stakeholders in the autism sector through the AAG to address a range of suggestions and recommendations for improving the scheme.

In addition, the NDIA established a specific sub-group under the Independent Advisory Council (**IAC**) to provide a forum for stakeholders to consider opportunities for further improvement. Both of these working groups are currently in the process of providing the NDIA with advice and recommendations. The Committee should note that these are issues that are being researched and investigated and that final recommendations have not been submitted to the NDIA or Disability Ministers. The work of these groups will be finalised over the next six months. The NDIA would be pleased to provide the Committee with further information on the outcomes of this work, once it has been considered by the NDIA and Disability Ministers, and proposes to provide an update to the Committee at that stage.

## 2 Autism in Australia

There is considerable peer-reviewed academic research about various aspects of the autism spectrum in Australia. Information about autism diagnostic practices in Australia, the prevalence of autism in Australia, and females with autism in Australia is presented below.

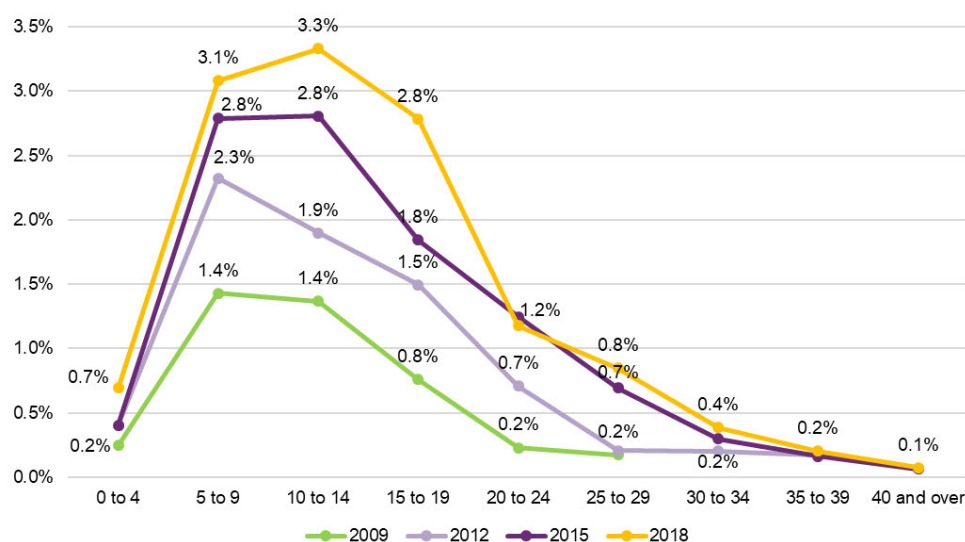
### 2.1 Prevalence of autism in Australia

In Australia, the prevalence of autism is in a constant state of change. This fluctuation is largely due to changes in diagnostic criteria and state/territory reporting requirements<sup>2</sup>. In 2019, the Australian Bureau of Statistics (ABS) published one of the most recent statistics about the prevalence of autism in Australia in the *Disability, Ageing, and Carers survey* (SDAC) report<sup>3</sup>. In 2018, according to the ABS:

- there were 205,200 Australians with autism, a 25.1 per cent increase from the 164,000 with the condition in 2015.
- males were 3.5 times more likely than females to have the condition, with prevalence rates of 1.3 per cent and 0.4 per cent respectively.

During 2009, the ABS published the SDAC report and in 2012, 2015, and 2018, the ABS published updated versions of this report. As illustrated in Figure 1, the prevalence of autism in Australia has been increasing. For example, SDAC reported that during 2009, 1.4 per cent of all 5 to 9-year-olds in Australia had autism. However, in 2018 this figure increased to 3.1 per cent

**Figure 1: Overall estimates from the Survey of Disability, Ageing and Carers (SDAC) for 2009, 2012, and 2018 from the Australian Bureau of Statistics**



Rates of autism increase to a peak around 5 to 14 years of age before declining at older ages. Rates have been increasing over time, for all except the oldest age groups.

There is conflicting information between state/territory and Commonwealth agencies about the prevalence of autism in Australia. In 2008, Williams and colleagues<sup>4</sup> showed that for the years 2003-

<sup>2</sup> Nassar, N., Dixon, G., Bourke, J., Bower, C., Glasson, E., De Klerk, N., & Leonard, H. (2009). Autism spectrum disorders in young children: Effect of changes in diagnostic practices. *International Journal of Epidemiology*, 38(5), 1245-1254. <https://doi.org/10.1093/ije/dyp260>

<sup>3</sup> Australian Bureau of Statistics (ABS) (2019). 4430.0 - *Disability, Ageing and Carers, Australia: Summary of Findings, 2018*.

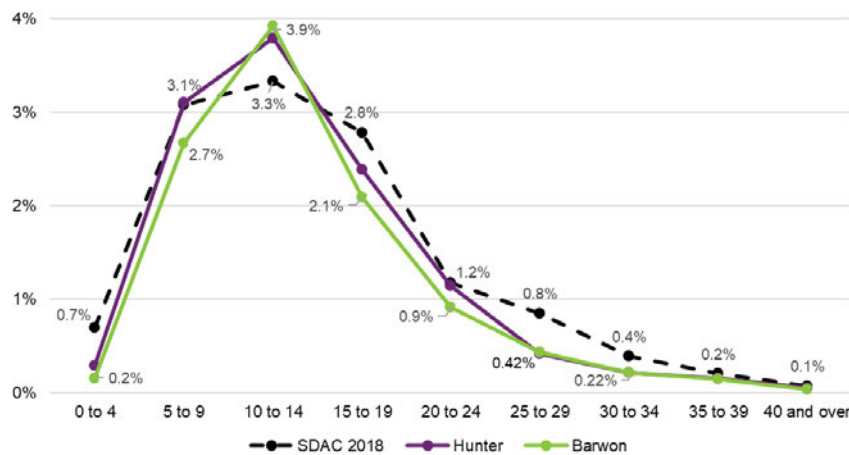
<sup>4</sup> Williams, K., MacDermott, S., Ridley, G., Glasson, E. J., & Wray, J. A. (2008). The prevalence of autism in Australia. Can it be established from existing data?. *Journal of Paediatrics and Child Health*, 44(9), 504-510. <https://doi.org/10.1111/j.1440-1754.2008.01331.x>

2004, State and Territory data reported the estimated prevalence of autism for 6 to 12-year-olds ranged from 9.6 to 40.8 per 10,000 children, while national data reported the prevalence of autism from 12.1 to 35.7 per 10,000 children. There was a similar variation in prevalence estimates for children aged 0-5 and 13-16 years. Based on these discrepancies, Williams et al. (2008) concluded:

*“Inconsistencies in autism prevalence estimates calculated from existing data sources suggest that further efforts are needed to ensure the collection of reliable information about the prevalence of ASD for national, State and Territory use.”*

The prevalence rates between autism in Australia and the prevalence of participants with a primary diagnosis of autism in the NDIS are similar. As illustrated in figure two, there is a considerable overlap between national autism prevalence rates and autism prevalence rates in the Hunter and Barwon regional test sites for the NDIS. Figure two not only illustrates the overlap between data provided by the ABS and rates of participants with autism in the NDIS, it also shows that children are more inclined to have a diagnosis of autism than adults. This finding adds credence to the notion that the NDIA should continue to develop and refine early intervention processes and strategies.

Figure 2: Comparison of Scheme prevalence with SDAC 2018: Hunter and Barwon

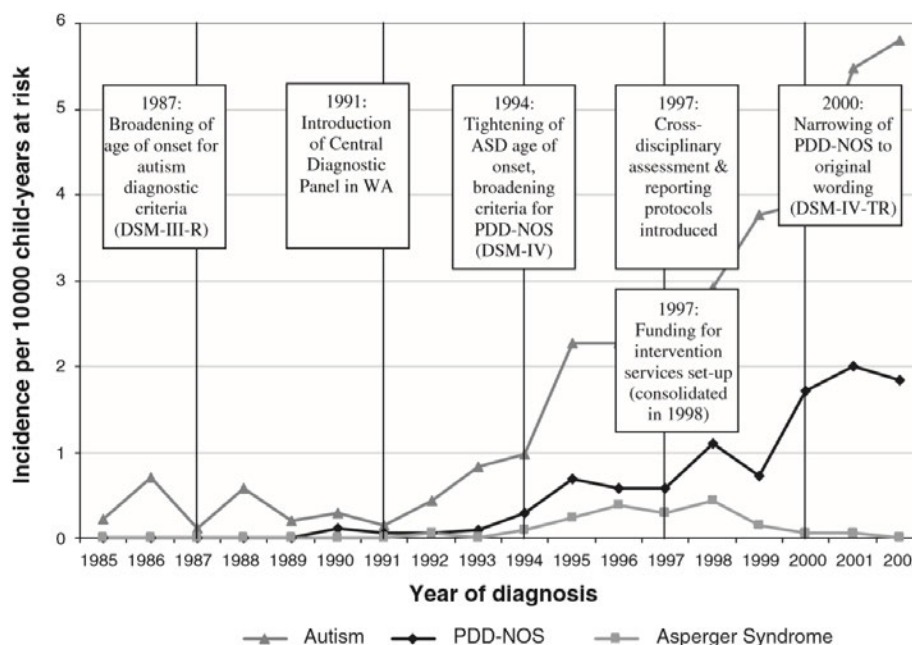


Hunter and Barwon rates are around 85-115% of SDAC 2018 rates\* between ages 5 and 24.

\* SDAC rates include all those who reported autism as a long-term condition (had lasted or was likely to last for six months or more).

Currently, it is difficult to predict the prevalence of autism in the Australian population since such rates are influenced by changing diagnostic criteria, reporting procedures, and government programs designed to support people with autism. As illustrated in figure three, within Western Australia the prevalence of autism spectrum disorders, in particular autism and Asperger syndrome, has changed with changes in State Government reporting procedures.

**Figure 3: Incidence and significant events in the diagnosis of ASD between 1985 and 2002 among children younger than eight years in Western Australia<sup>5</sup>**



## 2.2 Females with autism in Australia

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. 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).

The NDIA recognises that within the field of autism research, there has been a focus on examining males with autism diagnosis. This focus has resulted in a lack of research about females with autism. One of the explanations to a gender bias in autism research, assessment processes, and support services is that autism symptoms tend to present differently in females. There is also evidence that females are better able to successfully 'camouflage' their autism symptomology, resulting in lower rates of diagnosis<sup>6</sup>. Although diagnosis is not a pre-requisite for children to receive supports through the ECEI gateway, or to become a participant in the NDIS, lower rates of diagnosis in females may mean that they are less likely to be referred to the NDIS.

<sup>5</sup> Nassar, N., Dixon, G., Bourke, J., Bower, C., Glasson, E., De Klerk, N., & Leonard, H. (2009). Autism spectrum disorders in young children: Effect of changes in diagnostic practices. *International Journal of Epidemiology*, 38(5), 1245-1254, p. 1250.

<sup>6</sup> Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism*, 21(6), 678-689. <https://doi.org/10.1177/1362361316671845>

## 2.3 Autism diagnostic practices in Australia

Receiving a timely autism diagnosis helps those diagnosed to access a wide range of medical and education services and supports provided by state, territory and national agencies. Despite the benefits of receiving a timely autism diagnosis, academic literature has shown that currently in Australia there is an inconsistent approach towards diagnosing autism and that diagnostic practices do not follow international best practice guidelines<sup>7,8,9,10</sup>.

According to Randall et al.<sup>11</sup> international best practice guidelines for diagnosing autism in children involves a team of professionals who are equipped with:

- (i) a full developmental history to elicit parental concerns;
- (ii) a physical examination of the child;
- (iii) evidence from teacher/childcare reports that the behaviours occur in more than one setting;
- (iv) assessment of a child's speech and language abilities;
- (v) assessment of general development and/or cognition; and
- (vi) diagnostic decision-making based on current diagnostic classification criteria for autism.

Despite these clear guidelines, Taylor and colleagues in 2016<sup>12</sup> reported that across Australia there was variability in diagnostic practices for autism. For instance, while some clinicians work within a multidisciplinary assessment team, others practise independently and rarely collaborate with other clinicians to make a diagnostic decision. Furthermore, only half of respondents in their study reported that during the diagnostic process, they used a standardised objective assessment tool such as the *Autism Diagnostic Observation Schedule*. Also a third of respondents indicated that they did not include measures of development, cognition and language in assessments when they suspected the person had autism. Finally, Taylor and colleagues reported that 17 per cent of medical practitioners stated that they have given a patient an autism diagnosis even though they did not meet the autism diagnostic criteria.

In response to these and other barriers, as well as ensuring that Australians receive a timely and international best practice autism diagnosis, the NDIA provided funding to the Autism CRC to develop 'A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia' (the Guideline). The Guideline was released by the Autism CRC in October 2018 and includes 70 recommendations to support clinicians who undertake diagnostic assessments that may result in

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<sup>7</sup> Hensel, S., Coates, C., Symeonides, C., Gulenc, A., Smith, L., Price, A. M., & Hiscock, H. (2016). Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. *Journal of Paediatrics and Child Health*, 52(5), 506-511. <https://doi.org/10.1111/jpc.13157>

<sup>8</sup> Randall, M., Albein-Urios, N., Brignell, A., Gulenc, A., Hennel, S., Coates, C., ... & Bayl, V. (2016). Diagnosing autism: Australian paediatric research network surveys. *Journal of Paediatrics and Child Health*, 52(1), 11-17. <https://doi.org/10.1111/jpc.13029>

<sup>9</sup> Skellern, C., McDowell, M., & Schluter, P. (2005). Diagnosis of autistic spectrum disorders in Queensland: Variations in practice. *Journal of Paediatrics and Child Health*, 41(8), 413-418. <https://doi.org/10.1111/j.1440-1754.2005.00667.x>

<sup>10</sup> Ward, S. L., Sullivan, K. A., & Gilmore, L. (2016). Practitioner perceptions of the assessment and diagnosis of autism in Australia. *Australian Psychologist*, 51(4), 272-279. <https://doi.org/10.1111/ap.12211>

<sup>11</sup> Randall, M., Albein-Urios, N., Brignell, A., Gulenc, A., Hennel, S., Coates, C., ... & Bayl, V. (2016). Diagnosing autism: Australian paediatric research network surveys. *Journal of Paediatrics and Child Health*, 52(1), 11-17. <https://doi.org/10.1111/jpc.13029>

<sup>12</sup> Taylor, L. J., Eapen, V., Maybery, M. T., Midford, S., Paynter, J., Quarmby, L., ... & Whitehouse, A. J. (2016). Diagnostic evaluation for autism spectrum disorder: a survey of health professionals in Australia. *BMJ Open*, 6(9), e012517. <http://dx.doi.org/10.1136/bmjopen-2016-012517>

an autism diagnosis. The Guideline does not seek to reform or replace the autism behaviours outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Diseases (ICD) diagnostic manuals, but rather provides a framework that enables an effective and efficient appraisal of these behaviours. DSS is leading work with the Department of Health, Department of Education, Skills and Employment and the NDIA to drive further uptake of the Guideline, and ensure it is being applied consistently across professions, sectors and jurisdictions.

## 2.4 Early detection and intervention

When infant child receives an autism diagnosis at an early age, their parents are more likely to receive appropriate referrals and support to implement a programs and strategies to maximise their child's potential. Early detection of autism is a crucial step towards enhancing the capacity and independence of a person with autism. Early detection of autism also gives parents time and resources to adjust and prepare for any future challenges that their children may encounter as they age from infancy into adolescence and then adulthood.

Failure to detect autism early can increase the prospect of the person with autism developing preventable conditions that can be severe and complex in nature. For instance, adults with autism have commented that had they received an autism diagnosis when they were younger, they might have avoided feeling depressed and anxious about being '*socially awkward*'.<sup>13</sup> They claimed that having an awareness of autism would have given them vital perspectives on how they have lived their lives as well as the confidence and skills to manage environmentally or socially challenging situations.

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## 3 Autism and the NDIS

### 3.1 Assessing individual need

The NDIS is responsible for supports that focus on a person's functional ability, including supports that enable a person with autism to undertake activities of daily living and participate in the community and social and economic life (rule 7.6 of the Supports for Participants Rules). The NDIA uses the following four complementary and cumulative methods in its process of determining the value of packages allocated to participants with autism.<sup>14</sup>

- (i) A validated functional assessment instrument. The two instruments used predominantly are the World Health Organisation's Disability Assessment Schedule (WHODAS 2.0) and the Living Skills Profile (LSP 16).
- (ii) Guided questions that collect information in regard to eight domains.
- (iii) Participant goals as specified in each participant's NDIS plan.
- (iv) A conversation between the participant, the NDIA planner and/or LAC on what the person wants and needs, and judgements by the planner or LAC about what is reasonable and necessary. The plan and the package value is reviewed periodically and unscheduled reviews can be requested if required.

NDIS plans are developed and approved to cover the full cost of supports where these are considered reasonable and necessary for the participant. The decision on what capacity building supports or therapies are deemed reasonable and necessary for an individual participant takes into account the responsibilities of the health system and services already available to the participant.

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<sup>13</sup> Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders*, 48(11), 3761-3772. <https://doi.org/10.1007/s10803-018-3639-1>.

<sup>14</sup> Australian Government Department of Social Services, "Joint Response to the South Australian Parliamentary Inquiry on Mental Health Services and the NDIS", part 5.

As of 30 June 2020, out of 391,999 participants in the NDIS 122,830 (31%) had a primary diagnosis of autism. In addition, the largest numbers of participants with autism in the NDIS were in the younger age brackets (i.e., 0 to 18 years of age). Although the average annualised committed support for participants with a primary diagnosis of autism is \$39,790, which is less than the average for all NDIS participants (\$70,070), in some age brackets, such as the 45 to 54 cohort, participants with autism received significantly more on average than the average for all NDIS participants (\$151,957 against \$112,791 respectively), despite making up a lower percentage of NDIS participants overall (only 3% of participants).

**Table 1 - Number of active participants with Autism as a primary disability, as at 30 June 2020 - compared to full Scheme by age group.**

Age	Primary disability autism		All Scheme		Autism % participants
	Active participants with an approved plan	Average annualised committed support	Active participants with an approved plan	Average annualised committed support	
0 to 6	20,427	\$25,500	61,961	\$24,080	33%
7 to 14	64,016	\$22,096	97,833	\$24,608	65%
15 to 18	15,838	\$46,157	29,251	\$52,896	54%
19 to 24	12,218	\$78,198	33,087	\$87,500	37%
25 to 34	6,476	\$110,299	35,639	\$110,284	18%
35 to 44	2,161	\$135,511	33,400	\$112,838	7%
45 to 54	1,107	\$151,957	41,610	\$114,940	3%
55 to 64	506	\$149,994	47,730	\$112,791	1%
65+	81	\$177,403	11,476	\$109,710	1%
<b>Total</b>	<b>122,830</b>	<b>\$39,790</b>	<b>391,999</b>	<b>\$70,070</b>	<b>31%</b>

### 3.2 Early Childhood Early Intervention (ECEI) approach and children with autism

The NDIA has designed the ECEI approach in line with best practice, using strong research and evidence. The NDIS ECEI approach aims to ensure all children aged 0-6 years with a developmental delay or disability get the best start in life.

The NDIS ECEI approach aims to help children with developmental delay or disability and their families achieve better long-term outcomes by supporting the development of the child through evidence-based interventions and building system capacity and family knowledge and confidence through the delivery of these supports. A key aim of best practice early intervention is to promote inclusion in a participant's local community.

In 2018, the NDIA undertook a major project titled the 'pathways project'. The project aimed to clearly articulate the key processes and decision points for people who would become participants of the scheme. In recognition of the unique needs of the very young participants of the scheme, the NDIA enhanced the existing ECEI approach into a formal ECEI Pathway for all children 0-6.

The pathway recognises that very young children and their family need a response from well-trained early childhood specialists to meet each family, and support them through what is often a very challenging and emotional time. The NDIS ECEI approach places a strong focus on family-centred planning and enables support to be accessed quickly and easily in a child's natural environments. Families with children aged 0-6 years with a developmental delay or disability are directed to an early childhood partner in their local area. Early childhood partners have demonstrated experience in early childhood intervention and provide assistance, advice and access to early intervention and support.

Children who require a longer term of early intervention support receive an individualised NDIS plan. Early childhood partners support families to request access to the NDIS, and once access is met, develop NDIS plans and support families to choose providers that best meet their child's needs.

The NDIS ECEI approach is designed to identify the type and level of early intervention support a child needs to achieve their best outcome. The type and level of supports is different for every child and their family according to their individual needs and circumstances.

- Children who require more intensive early intervention support for a period of time will be funded to receive the supports they need. The intensive support requested is considered where there is evidence, through the context of family centred principles and best-practice, that the early investment will result in positive life-long functional outcomes for the child.
- For children who do not meet eligibility for the NDIS, EC Partners make referrals to mainstream services such as health services, early childhood education services and school systems, as well as community supports and playgroups.

Regardless of the type and level of support received, a child's progress will be regularly monitored and the early childhood partner and service providers will work with the child and family towards improving the child's independence and participation in everyday activities.

### **3.3 Seven to 17 year old NDIS participants with autism**

The NDIA recognises the need to provide different supports at life transition stages for people with autism as they move to primary school, secondary school, ongoing learning and training or employment. Challenges at life stage transitions for many people with autism can include social exclusion, bullying, and encountering education systems and employers that do not understand or apply inclusive principles and practices.

The largest cohort of NDIS participants with autism are those of school age. Successful graduation and movement into further study or learning opportunities, whether it be via university, TAFE, or another institution, can greatly enhance employment outcomes for people with autism.

The teenage years are often a challenging time for teenagers, including those with autism, and for their parents and other close family. Key challenges include change and transition from primary to secondary school. For people with autism, self-identity, social inclusion and bullying are areas of significant risk. Many children with autism experience isolation and negative life experience often resulting in escalating behaviours of concern through this part of their life.

Some supports funded under the NDIS, including behavioural supports and capacity building supports aimed at increasing a participant's independence and social and economic participation, may support school aged participants with autism to develop general life skills that enhance their participation in the school and higher education systems. However the NDIA recognises there remain some areas at the NDIS and education interface that require further work, and will continue to collaborate with Disability Ministers and state and territory governments to resolve these issues. Improved integration and collaboration between all service systems supporting children and young people with autism will ensure they are fully supported to achieve their educational goals and maximise their economic potential.

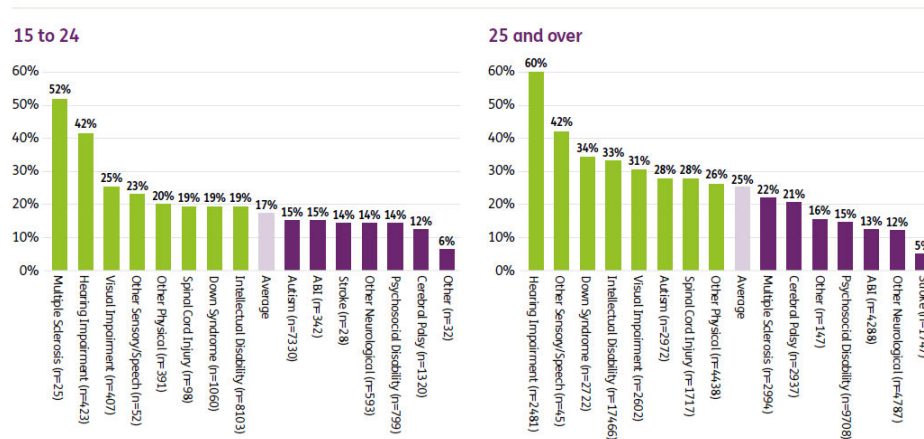
Commonwealth policies and programs administered by the Department of Education, Skills and Employment (DESE) for students with disability, including students with autism, are outlined in the joint submission provided by DSS, DESE and the Department of Health.

### 3.4 Adult NDIS participants with autism

#### Employment

International research has shown that adults with autism often encounter suboptimal employment outcomes relative to those who have other disabilities, such as learning disabilities.<sup>15</sup> This finding is also reflected in a special report the NDIA released about participants with a primary diagnosis of autism titled, '*Outcomes for participants with Autism Spectrum Disorder (ASD)*'<sup>16</sup>. In this report, 15% of NDIS participants with autism aged 15 to 24 were in employment, which was below the average of 17% of NDIS participants with disabilities in general. In contrast, 28% of NDIS participants with autism aged 25 and over were in some form of employment, which was above the average of 25% of NDIS participants with disabilities in general (see figures 4 and 5).

Figures 4 and 5: NDIS participants in employment



#### Explanation of graphs 4 and 5

- 15 per cent of participants with autism aged 15 to 24 have a paid job, slightly lower than the overall average of 17 per cent.
- 28 per cent of participants with autism aged 25 and over have a paid job, slightly higher than the overall average of 25 per cent.

In response to low employment rates among NDIS participants, on 7 November 2019, the Minister for the NDIS, the Hon Stuart Robert MP, released the *NDIS Participant Employment Strategy*.

Under this strategy, there are five key focus areas:

1. Increasing participant aspiration and employment goals in NDIS plans
2. Increasing participant choice and control over pathways to employment
3. Increasing market innovations that improve the path to paid work
4. Improving confidence of employers to employ NDIS participants
5. Leading by example as an employer.

<sup>15</sup> Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(9), 931-939. <https://doi.org/10.1016/j.jaac.2013.05.019>

<sup>16</sup> <https://data.ndis.gov.au/media/1564/download>.

### 3.5 Information, Linkages and Capacity (ILC) building

Since 2017, people with autism have been able to access support through organisations delivering Information, Linkages and Capacity Building funded projects. LACs provide the local face of ILC, connecting people with disability to their local community, services and programs. Details on projects supported through ILC that have had a focus on autism is provided at Appendix C.

The *ILC Strategy towards 2022* is designed to ensure all people with disability have greater access to information and supports, regardless of whether they are eligible for NDIS. This investment approach is designed to ensure:

- (i) People with disability, their family and carers benefit from a more inclusive, accessible and connected Australia. It does this by playing a significant part in building the capacity of:
  - a. Individuals – making sure people with disability and their families have the skills, resources and confidence they need to participate in and contribute to community, creating capacity.
  - b. Communities – making sure mainstream services and community organisations become more inclusive of people with disability, building opportunity.

ILC funds organisations to deliver activities in one of the following four complementary funding programs:

- (i) **Individual Capacity Building Program:** enabling systematic, nationwide access to peer support, mentoring and other skills building for people with disability, carers and families.
- (ii) **National Information Program:** ensuring people with disability, their families and carers have access to up-to-date, relevant information linking them to supports and services in the community.
- (iii) **Economic and Community Participation Program:** connecting people with disability to activities and community supports and opportunities, helping communities and employers to be inclusive and responsive to people's needs locally and nationally.
- (iv) **Mainstream Capacity Building Program:** building the capacity, knowledge, skills, practices and cultures of mainstream services so they have the skills to meet the needs of people with disability through short term catalyst investments.

ILC also helps prevent, reduce or delay the need for people with disabilities to access specialist disability services by improving their access to community and mainstream services. It does this by building the skills and capabilities of individuals to participate and contribute to the community and economy, which improves the sustainability of the NDIS. Administrative responsibility for ILC has now moved to the Department of Social Services.

### 3.6 Key challenges for the NDIS now and into the future

The NDIA continues to work with the Commonwealth and states and territories to resolve issues arising at the interface of the NDIS and other Commonwealth and state and territory services. The NDIA's role is to develop individualised plans for participants that address the functional impact of their disability, so participants can reach their social and economic potential. NDIS supports are designed to work in concert with, but not replace, existing services that are offered to participants, such as those provided by educational institutions, public or private hospitals, or correctional facilities.

The social characteristics of autism can make it difficult for people with autism to access and interact with the many systems and agencies involved in providing the supports and services they require. The NDIS supports participants to access mainstream systems through LACs, who provide information about, and referrals to, mainstream services for both NDIS participants and non-participants, while some participants receive funded support coordination in their NDIS plans, which can support their engagement with mainstream services. In addition, the NDIA now has in place

Health Liaison Officers and Justice Liaison Officers in every jurisdiction, who provide support to participants moving into and out of these state systems. However the NDIA recognises there is still work to be done with the Commonwealth and state and territory governments to ensure NDIS participants with autism are supported to access mainstream systems equitably, and will continue working with all actors at the state and territory and national level to improve outcomes.

## 4 Improving the NDIA's responsiveness to the needs of people with autism

### 4.1 Overview

The NDIA has undertaken a range of initiatives and investments to improve participant experience of the NDIS over the past three years. Many of these have been applied across the breadth of the NDIS and some have been autism-specific. As part of its efforts to improve the experience for participants with autism in the NDIS, the NDIA has been undertaking the following efforts.

- (i) **Better information:** providing information for participants, carers, providers and health professionals to make it easier to understand how people can access the NDIS and the type of evidence required to support access. <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-support-your-request/types-disability-evidence>
- (ii) **More knowledgeable and skilled staff:** upskilling its workforce by way of training and support to NDIA staff and LACs to better understand autism. All new NDIA staff receive this training.
- (iii) **Greater awareness of quality inclusive early childhood intervention:** working with DSS and the organisations funded through the Autism Specific Early Learning and Care Centres providing early learning programs and specific support for children aged zero to six years with autism in a long day care setting. The centres also provide parents with support in the care of their children and give them the opportunity to participate more fully in the community.
- (iv) **Flexible supports:** providing flexible participant plans, given the often changing nature of autism. This effort is underway for the adult life stages.
- (v) **Independent research commissioned** from the Autism CRC to provide a synthesis of theoretical and clinical evidence for early intervention approaches for autism.
- (vi) **Translated information** for people from Culturally and Linguistically diverse backgrounds
- (vii) **Community Connectors** to support people who find it hard to understand and navigate NDIA.

### 4.2 Consulting with key autism stakeholders via the Autism Advisory Group (AAG)

In 2018, the then Minister for Social Services, the Hon Dan Tehan MP, announced the establishment of the Autism Advisory Group (AAG). The goal of the AAG is to provide a strong voice on behalf of people with autism who are participating in the NDIS. The AAG has representatives from the Autism CRC, Amaze, Autistic Self- Advocacy Network - Australia and New Zealand (ASAN), Australian Advisory Board on Autism Spectrum Disorder (AABASD) and the Australian Autism Alliance. The AAG reflects the NDIA's commitment to consult and work with autism experts, service providers, and people with autism.

The AAG work focus has resulted in increased understanding among members of the NDIA's Senior Leadership Team about some of the issues that affect people with autism when they interact with the NDIA. The current areas of work focus for 2020 include –

- ECEI Strategy Reset;
- Reasonable and Necessary (R&N) Project;
- Intensive Behaviour Supports;

- Functional Capacity Assessments; and
- Participant Employment Strategy.

#### **4.3 Other consultation approaches**

Since November 2018, a series of ongoing and comprehensive consultations have occurred between the NDIA and key stakeholders within the Australian community who provide important services to people with autism and their families. The following organisations are routinely consulted:

- Autism Association of Western Australian Government
- Autism West
- AMAZE
- AutismSA
- AutismQLD
- Autism Tasmania
- Autistic Self Advocacy Network of Australia and New Zealand
- AutismCRC
- Autism Advisory and Support Service
- Aspect
- Autism Aspergers Advocacy Australia (A4)
- Autism Family Support Association (AFSA).

One purpose of these consultations is to convey to key stakeholders important policy developments that can impact participants with autism and their families; for example, the NDIA's response to COVID-19. These consultations also help the NDIA develop appropriate policies that can assist participants with autism and their families.

#### **4.4 Pathway improvements**

##### **(a) Consultation process**

The NDIA is working with the Autism sector through Autism Advisory Group in key areas to implement a number of pathway enhancements to improve outcomes for people with autism. In 2018, the NDIA engaged with the AAG to conduct a number of consultations to inform the design of a specialised NDIS ECEI pathway to improve the experiences of children and their families being supported by the Scheme. The NDIA held national consultation workshops in 2018 that were well attended by Autism sector representatives.

##### **(b) Complex Support Needs Pathway**

A participant experiences the NDIS through the 'participant pathway'.

The pathway is the journey that a person with disability will take from learning about the NDIS and understanding whether it is right for them and whether they are eligible, to building a plan that supports them to progress their goals and using that plan to achieve certain outcomes. NDIS pathways represent the way that participants and providers engage with the NDIS, from their first interaction through to ongoing engagement.

The Complex Support Needs Pathway was established in November 2018 to provide more specialised support for participants whose capacity to engage with the NDIS is affected by situational or personal factors, such as mental health issues, homelessness or incarceration. The Complex Support Needs Pathway is also likely to capture people with autism who have more complex support needs.

##### **(c) Key features of the Complex Support Needs Pathway**

The Complex Support Needs Pathway includes specialised planning teams, NDIA liaison officers and support coordinators – these are people who have the networks, skill and knowledge of government and community services to provide the support required for complex needs, including those specific to

people with autism.

The Complex Support Needs Pathway includes six key features to deliver better outcomes:

**(i) Pre-access, local engagement and strengthening connections to other services**

Strengthening local engagement and liaising with other government services and the community support clear pathways and connections into the NDIS and ensure that participants experience a 'joined up' approach to their support.

**(ii) Access, detailed handovers and connections**

Detailed handovers from States and Territory systems, existing service providers or 'hard to reach' support workers at the point of access, and streamlined access decisions using local NDIA Liaison and Specialised Planners.

**(iii) Complex Support Practice Lead and Planners**

Planning conversations with NDIS participants and other stakeholders, led by a NDIA planner with skills and experience in autism, focused on ensuring deep understanding of each participant's life circumstances.

**(iv) Skilled Support Coordinators and effective plan implementation**

A stronger focus on maintaining a participant's critical supports through a skilled Support Coordinator to assist with the development of service plans and agreements. This will mitigate the risks of service failure and improve coordination with other government services and community support systems.

**(v) Ongoing monitoring and evaluation**

Regular monitoring and evaluation of the plan, and participant outcomes, with the ability to make minor adjustments to supports and approaches to improve effectiveness.

**(vi) Review outcomes and progress**

Plan reviews measure participant progress toward outcomes, acknowledge achievements and adjust the participant's plan to support their next set of goals and outcomes, including assessing if the participant should remain in the Complex Support Needs Pathway or transition to the general NDIS Pathway.

## **4.5 Improved NDIA organisational and staff capabilities**

**(a) New organisational arrangements**

The NDIA has put into place the following arrangements to improve the management of services for participants with autism in the NDIS.

- (i) New organisational arrangements have been established to focus on the continual improvement of the NDIA's processes for access, planning and plan review. For example piloting IFAs, providing multiple channels for engagement, directed by participants' personal choices, and training of NDIA staff to support people with autism to navigate NDIS processes.
- (ii) Strategic planning and stakeholder engagement is actively managed through the Advice, Research, and Evaluation (ARE) Division. This engagement includes a broad range of grassroots and participant-led groups. This approach assists the NDIA to develop more autism-friendly processes and interactions.

- (iii) Establishment of a Participant Employment Taskforce with DSS to examine strategies for improving employment rates for people with disabilities, including people with autism.

#### **(b) Staffing and Recruitment Strategy**

Recognising its role in leading and encouraging inclusive practices, the NDIA is developing an Autism Staffing and Recruitment Strategy. This strategy will guide and direct the suite of actions required to build an NDIA workforce with the capabilities to better support participants with autism, service providers, and health professionals involved in NDIS processes.

The NDIA has implemented learning and development approaches to build the capability of staff and partners to support people with autism, while longer-term initiatives such as the Staffing and Recruitment Strategy mature.

The Staffing and Recruitment Strategy entails:

- (i) employing planners with skills in working with people with autism;
- (ii) adjusting contracts with partner organisations to encourage the employment of LACs with autism expertise; and
- (i) employing and engaging (on a contractual basis) staff with high levels of technical expertise in autism as Subject Matter Experts (SMEs).

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## **5 The NDIA's contribution to improving outcomes for people with autism in Australia**

### **5.1 Person centred -planning**

Person-centred planning (PCP) is a set of approaches designed to assist an individual to plan their life and supports. It is most often used for life planning with people with learning and developmental disabilities, though recently it has been advocated as a method of planning personalised support with many other sections of society who find themselves disempowered by traditional methods of service delivery, including children, people with autism, people with mental health issues and older people. PCP is accepted as evidence based practice in many countries throughout the world.

To support more equitable access and planning processes, the NDIA is working to implement Independent Functional Assessments (IFAs). IFAs will use disability-neutral tools to assess levels of functional impairment in participants and prospective participants. In situations where a person has no diagnosis, or has multiple diagnoses, disability-neutral assessment tools will provide important evidence of functional impairment to support more equitable access and planning processes for NDIS participants, including those with autism.

The rollout of IFAs will support better and more equitable planning processes that result in improved outcomes for all participants, including those with autism. Better integrating planning with other systems for participants will be a key feature of the NDIA's approach to improving planning processes under the NDIS.

### **5.2 Introduction of reasonable and necessary guidance on best practice in behaviour support**

The NDIA acknowledges that for most specialist and social models of support for people with autism, there are no nationally agreed frameworks or principles of practice or evidence. This gap in agreed evidence and guidance in a market driven insurance scheme can lead to highly contested interpretations of reasonable and necessary supports. The lack of frameworks and principles complicates notions of choice and control for participants and their families and carers, who may receive conflicting information about different practices, particularly in the early childhood space.

In a recent Cochrane review paper on the evidence base in early childhood intervention for behaviour support, the NDIA noted the high contestability of what constitutes valid evidence in making

reasonable and necessary judgements for participants in early childhood intervention.

[https://www.cochrane.org/CD009260/BEHAV\\_early-intensive-behavioral-intervention-eibi-increasing-functional-behaviors-and-skills-young](https://www.cochrane.org/CD009260/BEHAV_early-intensive-behavioral-intervention-eibi-increasing-functional-behaviors-and-skills-young)

The paper showed weak evidence for many behaviour support studies focused on Applied Behaviour Analysis (ABA). Of all the studies considered by the review, there were only five that were found to be valid, and within those five, all studies were assessed as having a high or very high risk for bias. All five studies were from pre-2011.

From 2011 to 2017, the review found 3,660 new papers (after removing duplicates), but only three reviews were determined to have relevant information about ABA. While it may appear that there is a clear body of evidence about ABA, in actual fact over the past 6 years, only a small amount of research has been published, all of it contestable. This review indicates there has been no actual new evidence in those 6 years.

In May 2020, the NDIA commissioned the Autism CRC to independently review evidence for the five main therapeutic (i.e. non-pharmacologic) intervention approaches for children with autism up to age twelve. The review will help to answer questions regarding the effects of these interventions on outcomes for children and their parents and caregivers.

The Autism CRC will complete their review in September 2020. The NDIA will develop a discussion paper using these findings and consult with stakeholders from across the autism sector and broader government in October and November 2020. Information from this review and stakeholder consultation will enable the NDIS to fund the most beneficial and ethical services for children with autism during their early development. A report from this project will be released to the public by end of December 2020.

### **5.3 Clarity and consistency of reasonable and necessary decisions guidance for early intervention.**

The NDIA is committed to making decisions that are in line with the reasonable and necessary criteria of the *National Disability Insurance Act 2013* (the NDIS Act). The NDIA has commenced a project to assist in the implementation of the Tune Review's recommendations about providing greater clarity and consistency with reasonable and necessary decisions. The above reviews will be included in the NDIA evidence repository and drawn on to inform the reasonable and necessary project.

The NDIA will also continue to work with governments and other key stakeholders, including the Autism CRC, to develop a national agenda of research for early intervention for children with autism.

### **5.4 Early Childhood Early Intervention (ECEI) Approach implementation reset**

The NDIA is conducting a reset of the ECEI approach to ensure NDIS supports for children and families with developmental delay and disability are positively influencing child and family outcomes.

The NDIA ECEI reset focuses on improving the specialised support for children with disability, autism, developmental delay and other additional needs. The reset is addressing issues such as:

- Early intervention should happen as soon as possible after a child's needs are identified. It might include therapies, education and other supports.
- Early childhood intervention should be evidence informed and clearly provide benefits for the child/family as well as life time care and support costs.
- Providing a stronger emphasis on capacity building for the child's care environment.
- The further development of an outcomes framework as a means of continually improving the Australian evidence base for early childhood intervention.

The reset is being undertaken to ensure that the NDIS works for very young children with developmental delay or disability and their families across all the different supports available under

the ECEI Approach. The NDIS is responding more flexibly to the support needs of very young children with early signs of autism and ensuring all enhancements use an approach of early engagement and support for children with the early signs of the likely presence of autism.

The reset will also provide a greater focus on the social model of disability and work with all mainstream systems for improvements to the inclusion of very young children in natural settings.

## **5.5 Improving linkages and referrals for people who are ineligible for NDIS**

The NDIA acknowledges that not meeting NDIS access requirements can be distressing for people with autism, particularly where they perceive or experience an absence of alternative services to support them with the impact of their condition. The NDIA is responding to this concern through practical changes, such as providing clear references to other sources of support in letters advising of ineligibility, as well as on a broader scale by developing linkages and referral protocols in collaboration with other funded Commonwealth services (Job Active, DES), LACs and the state and territory governments.

## **5.6 COVID-19 research project**

The NDIA is working with the University of Melbourne on a new survey about the changes that were made to the NDIS in response to COVID-19. The survey gives participants, their families and carers a chance to share their experience of interacting with the NDIA and the Scheme during the COVID-19 pandemic. The survey will also assist the NDIA to understand how NDIS participants have found using telehealth to access allied health services.

Through discussions with the AAG, senior members of the NDIA have learnt first-hand some of the issues that people with autism have encountered during the COVID-19 pandemic. These issues include providers withdrawing supports due to concerns their staff may contract COVID-19. In response to the withdrawal of services several people with autism had to reprioritise activities in their lives, which they reported impacted their social and economic participation. This work will be used to improve flexibility of funded supports and ensure planning, plan review and associated processes are as accessible and smooth as possible.

Members of the AAG have also provided key insights into the challenges that some participants with autism have encountered during the COVID-19 pandemic. For example, the increased social anxiety that they have encountered when supports have been withdrawn or offered via other means e.g. virtually, due to social distancing requirements.

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## Appendix A - Supports provided under the NDIS

### 5.7 Overview

Before determining which supports are reasonable and necessary, the NDIA will thoroughly explore what supports are currently being provided, or should reasonably be provided by informal and community supports and mainstream support systems.

- (i) **Informal supports** are supports that are provided by carers, family or friends. The NDIA recognises the vital role informal supports play in supporting people with disability, including NDIS participants.
- (ii) **Mainstream and community supports** are available to all members of the Australian community regardless of whether they have a disability or not. For example, supports provided or funded through the health, education or transport systems. The specialist disability supports that the NDIS funds complement the mainstream services that the Commonwealth, state, and territory governments provide, such as health, education, housing, transport and safety.

A participant's NDIS plan may include a range of supports provided by informal, mainstream and community networks.

Informal and mainstream supports are critical to the financial sustainability of the NDIS, and the NDIS is intended to complement, not replace, these supports. Before any funded support is added to a participant's plan, the NDIA must be satisfied that the support is most appropriately funded through the NDIS.

### 5.8 NDIS funded supports and interface with mainstream supports

The NDIS funds supports that are reasonable and necessary to assist a person with disability to undertake activities of daily living. These include:

- (i) assistance with planning, decision-making and household tasks;
- (ii) assistance to build capacity to live independently and achieve their goals, such as building social relationships, as well as financial management and tenancy management skills; and
- (iii) supports to engage in community activities such as recreation, education, training and employment.

NDIS participants can choose to access their funded supports through centre-based services, in-home services, day services, community access and outreach services.

The NDIS also recognises it needs to take into account and respond to varying, and at times fluctuating, levels of disability associated with mental health conditions. The planning process is flexible and can respond to the varying support needs of the individual. An individual will be able to access more practical support when needed and less when not required.

The health system is responsible for assisting participants with clinical and medical treatment. In particular, the health system is responsible for:

- (i) treatment of mental illness including acute inpatient, ambulatory, rehabilitation/recovery and early intervention, including clinical support for child and adolescent developmental needs;
- (ii) residential care where the primary purpose is for time limited follow-up linked to treatment or diversion from acute hospital treatment;
- (iii) the operation of mental health facilities;

- (iv) the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions;
- (v) all medical and clinical services, general practitioner services, medical specialist services, nursing, allied health services, preventive health care, care in public and private hospitals, and pharmaceuticals (available through the PBS);
- (vi) supports relating to a co-existing mental health condition where such supports, in their own right, are the responsibility of that system (e.g. treatment for a drug or alcohol issue); and
- (vii) other health related services, such as dental care, palliative care and nursing care.

Individuals and families sometimes need to fund medical and clinical services, such as out of pocket expenses or gap payments. The NDIS does not cover these costs.

The NDIS supports people with a permanent and significant functional impairment because of their disability, including psychosocial disability. People with early signs of a mental health issue are helped by the health system in the first instance. This is because the health system diagnoses and manages emerging mental health issues. The NDIS only funds early intervention supports where they are likely to reduce the participant's future need for support. These supports are generally not the type of help a person requires upon the first signs of a mental health issue. Early intervention supports funded by the NDIS are usually supports directed towards increasing the participant's independence, and social and economic participation.

## **5.9 How is the decision made to include supports?**

### **(a) General considerations**

The NDIS funds reasonable and necessary supports relating to a person's disability to help them achieve their goals and meet their needs. What is reasonable and necessary is set out in Section 34 of the NDIS Act.

A range of factors are taken into account in deciding whether to include any general or 'reasonable and necessary support' in a participant's plan, including whether the support:

- (i) is most appropriately funded or provided through the NDIS, and is not more appropriately funded or provided through other service systems;
- (ii) is related to the participant's disability (for example, it is expected that the NDIA will generally not fund household items that are not related to a participant's functional limitations and would usually be purchased by any person, i.e. general household furniture or appliances); and
- (iii) relates to day-to-day living costs, for example rent, groceries or utility fees that are not attributable to a participant's disability support needs.

To guide the consideration of NDIS supports provided to people with autism, the NDIA is informed by research literature and available evidence.

### **(b) Informal networks**

Before any support is added to a participant's plan, the NDIA must also be satisfied that the funding or provision of the support takes into account what kind of supports are reasonable to expect families, carers, informal networks or the community to provide (section 34(1)(e) of the NDIS Act).

For a participant who is a **child**, the NDIA must consider:

- (i) that it is normal for parents to provide substantial care and support for children (rule 3.4(a)(i) of the *National Disability Insurance Scheme (Supports for Participants) Rules 2013* (**Supports for Participants Rules**));

- (ii) whether, because of the child's disability, the child's care needs are substantially greater than those of other children of a similar age (rule 3.4(a)(ii) of the Supports for Participants Rules);
- (iii) the extent of any risks to the wellbeing of the participant's family members or carer or carers (rule 3.4(a)(iii) of the Supports for Participants Rules); and
- (iv) whether the funding or provision of the support for a family would improve the child's capacity or future capacity, or would reduce any risk to the child's wellbeing (rule 3.4(a)(iv) of the Supports for Participants Rules).

For a participant who is an **adult**, the NDIA must consider:

- (i) the extent of any risks to the wellbeing of the participant arising from the participant's reliance on the support of family members, carers, informal networks and the community (rule 3.4(b)(i) of the Supports for Participants Rules);
- (ii) the suitability of family members, carers, informal networks and the community to provide the supports that the participant requires, including such factors as:
  - (A) the age and capacity of the participant's family members and carers, including the extent to which family and community supports are available to sustain them in their caring role (rule 3.4(b)(ii)(A) of the Supports for Participants Rules);
  - (B) the intensity and type of support that is required and whether it is age and gender appropriate for a particular family member or carer to be providing that care (rule 3.4(b)(ii)(B) of the Supports for Participants Rules); and
  - (C) the extent of any risks to the long-term wellbeing of any of the family members or carers. For example, a child should not be expected to provide care for their parents, siblings or other relatives or be required to limit their educational opportunities (rule 3.4(b)(ii)(C) of the Supports for Participants Rules); and
- (iii) the extent to which informal supports contribute to or reduce a participant's level of independence and other outcomes (rule 3.4(b)(iii) of the Supports for Participants Rules).

For all participants, the NDIA must also consider the desirability of supporting and developing the potential contributions of informal networks within their communities (rule 3.4(c) of the Supports for Participants Rules). The NDIS may fund supports that are needed as a direct result of a participant's disability, but is not intended to displace the ordinary role of parents, families and carers.

The ongoing capacity of family and carers is critical to the wellbeing of some participants. The amount and intensity of support required, and other factors, such as illness and ageing, can place a carer's wellbeing at risk and compromise their capacity to continue in their caring role.

The NDIA understands that sustaining informal support can be an integral component of meeting a participant's needs and the NDIA aims to increase the community participation of participants within the context of their families and existing support networks.

### **(c) Support most appropriately funded or provided through the NDIS**

Before any support is added to a participant's plan, the NDIA must also be satisfied that the support is most appropriately funded or provided through the NDIS, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

- (i) as part of a universal service obligation; or

- (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability (section 34(1)(f) of the NDIS Act).

Whether or not funding is available through other general systems is *not* the test of whether a support is most appropriately funded or provided under the NDIS.

For example, the fact that the health system does not fund entirely, or even at all, what is essentially clinical treatment, or some other form of support that is more appropriately funded through the health system, does not make the provision of such a support the responsibility of the NDIS.

The considerations that the NDIA must take into account when deciding whether a support is most appropriately funded through the NDIS, are outlined in Schedule 1 to the Supports for Participants Rules under the following headings:

- (i) Health (excluding mental health);
- (ii) Mental health;
- (iii) Early childhood development;
- (iv) Child protection and family support;
- (v) School education;
- (vi) Higher education and vocational education and training;
- (vii) Employment;
- (viii) Housing and community infrastructure;
- (ix) Transport; and
- (x) Justice.

The considerations set out under these headings are derived from the principles to determine the responsibilities of the NDIS and other service systems, agreed to by the former Council of Australian Governments (**COAG**) in 2015.

While this information outlines the considerations relevant to whether a support is more appropriately provided or funded through another service system, it does not purport to impose any obligations on another service system to fund or provide particular supports.

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## 6 Appendix B - Plan Development and Review

Each participant in the NDIS will have a plan that is prepared in conjunction with the participant and approved by the NDIA.

The planning process seeks to identify the individual needs of NDIS participants and determine the range of informal, community, mainstream and NDIA funded supports needed to progress towards their goals.

A participant's plan is made up of two parts:

- (i) the participant's **statement of goals and aspirations**, which is prepared by the participant and specifies their goals, objectives, aspirations and personal context (including all informal, community and other mainstream supports already available to the participant); and
- (ii) the **statement of participant supports**, which is prepared with the participant and approved by the NDIA, which specifies, among other matters, the supports that will be funded by the NDIS.

A participant's Statement of Participant Supports will also set out the date by which the NDIA will review a participant's plan (i.e. create a new plan) and how the funding for supports under a participant's plan will be managed.

### (a) When must the NDIA prepare a participant's plan?

When a person becomes a participant, the NDIA *must* facilitate the preparation of the participant's plan. Therefore, every participant in the NDIS will have a plan prepared on their behalf by the NDIA.

### (b) The participant's Statement of Goals and Aspirations

A participant's plan *must* include the participant's Statement of Goals and Aspirations prepared by the participant that specifies:

- (i) the goals, objectives and aspirations of the participant (section 33(1)(a), NDIS Act); and
- (ii) the environmental and personal context of the participant's living, including the participant's:
  - (A) living arrangements (section 33(1)(b)(i), NDIS Act);
  - (B) informal community supports and other community supports (section 33(1)(b)(ii), NDIS Act); and
  - (C) social and economic participation (section 33(1)(b)(iii), NDIS Act).

### (c) What is the importance of the participant's Statement of Goals and Aspirations?

The participant's statement of goals and aspirations is the important first step in preparing the participant's plan.

The participant's Statement of Goals and Aspirations is critical to the development of a successful Statement of Participant Supports.

The NDIS Act requires that:

- (i) the NDIA *must* have regard to a participant's Statement of Goals and Aspirations when deciding to include supports in a participant's plan (section 33(5)(a), NDIS Act); and

- (ii) before including *any* support in a participant's plan, the NDIA *must* also be satisfied that the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's Statement of Goals and Aspirations (section 34(1)(a), NDIS Act).

Therefore, the link between participant's Statement of Goals and Aspirations and the Statement of Participant Supports is explicit, and ensures that the participant's statement provides the important foundation for the subsequent selection of supports.

#### **(d) The Statement of Participant Supports**

A participant's plan *must* include a Statement of Participant Supports, prepared with the participant and approved by the NDIA, that specifies:

- (i) the general supports (if any) that will be provided to, or in relation to, the participant (section 33(2)(a), NDIS Act);
- (ii) the 'reasonable and necessary' supports (if any) that will be funded under the NDIS (section 33(2)(b), NDIS Act);
- (iii) the date by which, or the circumstances in which, the NDIA must review the plan (see setting the plan review date) (section 33(2)(c), NDIS Act);
- (iv) the management of the funding for supports under the plan (section 33(2)(d), NDIS Act); and
- (v) the management of other aspects of the plan (section 33(2)(e), NDIS Act).

#### **(e) What are 'reasonable and necessary' supports?**

'Reasonable and necessary' supports refer to the supports in a participant's plan which are funded under the NDIS.

'Reasonable and necessary' supports for people with disability should:

- (i) support people with disability to pursue their goals and maximise their independence (section 4(11)(a), NDIS Act);
- (ii) support people with disability to live independently and be included in the community as fully participating citizens (section 4(11)(b), NDIS Act); and
- (iii) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment (section 4(11)(c), NDIS Act).

The NDIA funds 'reasonable and necessary' supports that help a participant reach their goals, objectives and aspirations, and to undertake activities to enable the participant's social and economic participation.

'Reasonable and necessary' supports are funded by the NDIS in a range of areas, which may include education, employment, social participation, independence and living arrangements.

#### **(f) Plan reviews**

Generally, a participant's plan is reviewed every 12 months. However, where circumstances change, there are certain specific circumstances where the NDIA is required to create a new plan for a participant. When a new plan is created, it replaces the old plan.

A new plan can also be created by one of the following ways:

- (i) by a participant changing their statement of goals and aspirations. A participant may do this at any time (NDIS Act, section 47); or

- (ii) the NDIA conducting a review of a participant's plan (NDIS Act, section 48). In addition to reviews that occur prior to the expiry of an existing plan, a review of a participant's plan can occur:
  - (A) when a participant requests a review (NDIS Act, section 48(1)); or
  - (B) at the initiative of the NDIA (NDIS Act, section 48(4)).

## 7 Appendix C - Information Linkages and Capacity Building

**Table 1 – Information Linkages and Capacity Building – National Information Program Grant Round**

As at July 2020.

Organisation	Project Title	Project Description
Amaze Inc.	Autism Connect	In consortium with ARTD Consultants, Autism Association of South Australia, Autism Tasmania Incorporated and Autism Awareness Australia, Amaze will deliver Autism Connect, a one-stop-shop providing independent evidence-based information, advice and assistance to all people with autism, their families, professionals and the NDIA. The service has been piloted in 2018-19 from an ILC grant and is ready to scale nationally. Autism Connect will use a multi-modal delivery - telephone, webchat, SMS, email and website information. The service is supported by an extensive Resource Repository of new and existing content developed and sourced nationally and internationally, overseen by an autistic advisory group and Neurodevelopmental Expert Panel.
Autism Association of South Australia	Autism Modules 4 Adults	The Autism Module Series 4 Adults project will consist of a digital library of modules specifically designed and developed by adults on the autism spectrum and experienced professionals, for the benefit of adults with autism and associated co-morbidities. These modules will be provided via an accessible digital platform allowing individuals throughout Australia, including rural and remote communities, to access relevant, evidence-informed self-development opportunities in a timely, secure and functional manner. Modules will focus on areas that are relevant for adults on the Autism Spectrum Disorder and will provide information, tips, strategies, resources and advice, including referral pathways for clients to relevant services. The individual modules will be developed based on current research into the most significant areas of information needs.

**Table 2 - Information Linkages and Capacity Building – 2019 Economic Participation of People with Disability Grant Round**

Organisation	Project Title	Project Description
Autism Queensland Limited	Autism EmplayABLE	<p>Autism EmplayABLE is an innovative project engaging with Australian businesses to: 1) build awareness of the positive attributes of employees on the autism spectrum 2) develop their capacity to successfully employ them.</p> <p>The pilot project will develop a model incorporating evidence-based autism-specific approaches that will be rolled out in collaboration with disability employment services nationally. Brisbane City Council and White's IGA stores (Sunshine Coast) have provided written expressions of interest in partnering with AQ for the pilot.</p> <p>Core project components include:</p> <ol style="list-style-type: none"> <li>1. training to assist businesses to understand the strengths and challenges of people on the spectrum, and appropriate workplace accommodations</li> <li>2. autism-specific audits to identify suitable positions and workplace accommodations</li> <li>3. on-the-job autism-specific coaching for employees on the spectrum that will in turn inform future training for businesses and workplace accommodations.</li> </ol> <p>Unique autism-specific features of this model will include the use of evidence-based practices such as Structured Teaching, Video Modelling, Social Narratives and workplace social skills development.</p>
La Trobe University	Improving employment opportunities and outcomes for autistic job seekers - Training disability employment service providers	<p>This project involves the development and evaluation of an innovative, evidence-based training package for Disability Employment Service (DES) providers to improve their capacity to cater to the unique needs of job seekers on the autism spectrum, to increase their prospects of securing and retaining suitable employment. This involves:</p> <ol style="list-style-type: none"> <li>a) undertaking a Training Needs Analysis (TNA) with DES providers and triangulating these data with information from people on the autism spectrum and their family members to determine the barriers and enablers in successfully placing and retaining them in the workplace.</li> <li>b) co-producing a training package with people on the autism spectrum (employed and unemployed) and DES professionals (from both urban/rural DESs) to enhance knowledge and understanding of job seekers on the autism spectrum and their workplace requirements.</li> <li>c) delivering the training to DES staff in one urban and one rural DES.</li> </ol>

		<p>d) evaluating the training package pre- and immediately post- delivery, and three months later to determine whether:</p> <ul style="list-style-type: none"> <li>• knowledge, understanding and confidence regarding Autism Spectrum Disorders and placing job seekers have improved</li> <li>• at three months, outcomes for these clients have improved.</li> </ul> <p>e) producing a report on the training package and evaluation following project completion, incorporating next steps for dissemination and utilisation.</p>
Rehab Management (Aust) Pty Ltd	BusyBeans Café	<p>BusyBeans Café is a social enterprise initiative offered by Rehab Management (RM) that promotes community participation for people with a moderate intellectual disability, or who are on the Autism spectrum, by providing work experience opportunities with supportive businesses.</p> <p>Participants will receive barista, job readiness and customer service training delivered by qualified barista trainers at 'coffee schools' across Australia. Once training is completed and the participants have achieved minimum quality standards, they will be placed with partnering businesses for paid work experience. These businesses will be screened as being disability inclusive.</p> <p>Support workers will accompany participants for as long as required to ease their transition into work experience. This project will empower participants and build their confidence and resilience by providing them work experience in safe, supportive environments. The skills they acquire will be transferrable for future employment. Employers will also benefit from promoting a more inclusive environment, allowing them to offer more opportunities to attract, employ and retain people with disability.</p> <p>On a wider scale, this project will boost social inclusion of people with disability, which benefits society as a whole.</p>
University of Sydney	Improving accessibility and training to deliver job opportunities for adults with Autism Spectrum Disorder	<p>The project will produce the first documented research evidence in Australia for implementing Workplace Change, Implementation and Evaluation Plans (WCIEP) to support individuals with Autism Spectrum Disorder (ASD) in employment. It will be undertaken via a partnership between the University of Sydney, Toll Group, Macquarie University and ASPECT who will conduct a two armed approach:</p> <p>Arm 1: Workplace evaluation and change:</p> <ul style="list-style-type: none"> <li>• Conduct a feasibility and implementation review to understand workplace needs, possible barriers to sustained employment, and identification of safe and diverse fully paid workplace roles with career development pathways.</li> <li>• Implement workplace change strategies, co-designed with community members, to support individuals with ASD to deliver inclusive workplace practices.</li> </ul> <p>Arm 2: Individual profiling and a Cohort Evaluation of Employment and Wellbeing to:</p> <p>Evaluate strengths of individuals with ASD and to use cognitive profiles to identify roles that will likely result in successful outcomes for the individual and employer, while supporting areas of documented weakness to improve sustainability.</p>

		Place 15 individuals with ASD into paid full-time positions, based on their cognitive profiles and interests.
Xceptional Testing Pty Ltd	Xceptional Partnership Accessibility Program	<p>The aim of this project is to deliver employer readiness, manager coaching and employee support to three employers (two in NSW, one in VIC) to support their efforts to hire and retain employees with Autism Spectrum Disorder (ASD). The project will result in the recruitment and placement of 20 individuals with ASD into Information and Communications Technology (ICT) roles with these employers, and ensure that these employers develop their internal capabilities to hire and retain more employees with ASD in the future.</p> <p>XPAP will include auditing corporate readiness for employing individuals with ASD, supporting change management, coaching line managers, supporting HR business partners, and providing ongoing coaching and support to candidates.</p>
YMCA of SA Youth and Family Services Incorporated	YMCA Employment Scaffold (YES)	<p>The YES project aims to review and change YMCA SA's recruitment and training methods, building on the organisation's current Leap programs for people with disability who have employment goals. Leap supports young people to develop independent living and social skills. Twelve people from Leap between the ages of 15 and 30 who have an intellectual disability or Autism Spectrum Disorder will be targeted. The project will recruit an experienced employment leader and two volunteers with disability to guide the development of recruitment and delivery of training processes for specific roles.</p> <p>The project will target 12 jobs across SA where YMCA provide services, which will include the Lower North and Fleurieu Regions.</p>
Darwin Community Arts Incorporated	Free Space Public Art Collective	<p>This pilot initiative will work with a select team of 6 artists with disability over 6 months (a 3-hour workshop/week) to develop a suite of artworks appropriate for installation in public spaces. The project will take participants through all aspects of the development of a public art project, including a workshop with professional artists, structured sessions with designer/s and fabricator/s to appropriately interpret and translate their artwork into another medium, and real work experience of delivering a large-scale arts project through to completion for local government.</p> <p>The Arts Access Darwin artists are a diverse group, artists in the group live with different disabilities, and some artists have complex or multiple disabilities, including: acquired brain injuries, autism spectrum disorder, cerebral palsy, hearing loss, physical disabilities, down syndrome and intellectual disabilities.</p> <p>Artists involved in this supported program will work as paid artists and have the unique opportunity to see their creative ideas develop into quality works for the broader community to experience.</p>

**Table 3 - Information Linkages and Capacity Building – 2018 Disabled People and Families Organisations (DPFO) grant round**

Organisation	Project Title	Project Description
Autism Northern Territory Incorporated	Autism Northern Territory Capacity Building 2019	<p><b>Organisational Capacity Building</b> Engage a consultant to facilitate organisational training and the development of resources for staff, committee members and volunteers to improve their leadership skills and strengthen the involvement of people with disability in the organisation.</p> <p><b>Individual Capacity Building</b> Employ a Project Officer to work on inclusive projects with schools and local businesses. Deliver peer-to-peer and mentoring programs in the Greater Darwin Area and explore options to deliver support programs in Katherine and Alice Springs. Collaborate with other stakeholders in the development and implementation of social programs in the Northern Territory.</p>
Autism Tasmania Incorporated	Peer Support the Autistic Way	<p><b>Organisational Capacity Building</b> Appoint a Project Manager to evaluate current models of peer support provision and to review existing research literature in order to determine an optimal model for facilitator induction and group formation in Tasmania.</p> <p><b>Individual Capacity Building</b> Design, implement and evaluate a pilot peer support program for adults on the autism spectrum in Tasmania. Develop and publish support materials on the Autism Tasmania website and establish a member-only portal for topic-specific forums.</p>
Autism West Support Incorporated	Inclusive People and Culture Strategy	<p><b>Organisational Capacity Building</b> Engage a HR specialist to advise, review and adjust current processes to accommodate a targeted growth in neuro-diverse staff and volunteers. The Autism West community will also be consulted to ensure a range of perspectives are encapsulated within their 'Inclusive People and Culture Strategy'.</p> <p><b>Individual Capacity Building</b> Develop and deliver an 'Identity and Self-awareness' training course. The course will be co-designed with the autism community, and will assist participants to identify their strengths and areas of interest, identify challenges and strategies to address those challenges, and inform their personal plan for employment, accessibility and</p>

		appropriate accommodations
Extended Families Australia Inc.	Capacity Building for the Vietnamese Community	<p><b>Organisational Capacity Building</b> Support an organisational capacity review of the Vietnamese Families with Special Needs Group (VFSNG) to enable the development of a strategic plan, including governance arrangements, risk management and documentation of systems, processes and policies. Provide leadership training and mentoring. Develop key resources, a website and social media presences to raise the profile of the organisation.</p> <p><b>Individual Capacity Building</b> Deliver a 15 week pilot program for six young adults (primarily with Autism) to provide opportunities for participants to develop interests, build confidence, independence, connection, motivation and community participation.</p>
I Can Network Ltd.	Enhancing Post-School Success for Autistic Young Adults	<p><b>Organisational Capacity Building</b> Develop resources to build practical life skills and provide self-advocacy tools to support young adults with Autism as they consider post-school options. The content will be developed and delivered online and face-to-face by experienced mentors with Autism.</p> <p><b>Individual Capacity Building</b> Deliver five face-to-face workshops in Melbourne, Sydney and Brisbane for neurodivergent young adults and their parents/carers, host live webinars to provide additional information and provide online peer mentoring.</p>
Interchange Outer East Incorporated	Different Journeys Social Connectedness Program	<p><b>Organisational Capacity Building</b> Support the Different Journeys Committee to revise corporate strategies and operational plans to incorporate expansion of their social connectedness and volunteer training programs. The project will enable the Committee to maintain on-going stakeholder relationships and build internal capability to continue exploring other partnership and collaboration opportunities.</p> <p><b>Individual Capacity Building</b> Deliver Different Journeys' social connectedness program in the Banyule area. The program will offer monthly peer support events for teenagers (13-18) and adults (18+) with autism. These events also serve as a training platform – participants have opportunities to join the events team and gain employable skills in areas such as events management, multimedia (photography and videography), social media, music performance, public speaking and events hosting.</p>
Plumtree Children's Services	Reframing Autism	<p><b>Organisational Capacity Building</b> Support Reframing Autism (RA) to become an incorporated association and to develop a constitution and appropriate governance structure, corporate plans and resources, including a website and information</p>

Incorporated		<p>management systems. Enable the employment of a part-time RA Peer Worker and support an annual symposium on inclusion and acceptance.</p> <p><b>Individual Capacity Building</b> Support Reframing Autism (RA) to develop and deliver a program of parent education events including workshops, training, an autistic-led parent retreat focused on developing parenting skills, and an annual symposium. Enable RA to establish mentoring relationships between autistic adults &amp; non-autistic parents, &amp; between parents.</p>
South West Autism Network Inc.	Building Individual Capacity to Navigate Support Services - South West WA	<p><b>Organisational Capacity Building</b> Engage a consultant to assist the organisation to register to provide NDIS Support Coordination services. Purchase a CRM system, and deliver training for staff to improve leadership, skills and capability in service delivery.</p> <p><b>Individual Capacity Building</b> Provide peer support to people with autism in the south west region of Western Australia, including information on NDIS processes, and mainstream and community services. The project will promote meaningful inclusion of people with disability in all aspects of local community life through social media, a website, e-newsletter to subscribers, and individually via phone, email and in-person meetings. Peer-led individualised and group activities to build capacity for self-management of plans and independence will be delivered, some in collaboration with other disability support services.</p>

**Table 4 - 2017 – Information Linkages and Capacity Building – 2018 Round 2 ILC Jurisdictional Grants ACT**

Organisation	Project Title	Project Description
ACT Playgroups Association Inc.	Playing Together - a family and inclusion support model for mainstream playgroups	The Playing Together (PT) program will be delivered to 30-50 mainstream playgroups in the ACT region, reaching over 300 families. The program educates mainstream playgroups to become more welcoming and inclusive; better supporting adults and children with additional needs to connect with their community and access important parent peer-support networks. The project will employ and train parents with disabilities or a lived experience of disability to work as play helpers. This will improve standards of practice within playgrounds, and also provides income, training and valuable work experience that can contribute towards future career pathways in children's or disability services.
ACT Playgroups Association Inc.	Ready2Play	Ready2Play (R2P) is an all abilities pre-sporting program for those aged 2-6 years, designed to include children with additional needs in mainstream sporting activities. R2P will develop and test a model of parent and coach-led sporting sessions, introducing children with additional needs to conventional sports alongside able-bodied children. Mainstream sporting activities will be adjusted so that children can be included without the need for specialised therapists, equipment or programs.
Autism Spectrum Australia (ASPECT)	Bridging the Gap	The project will develop and deliver an autism training package to the ACT community policing division of the Australian Federal Police. Face to face and on-line training will increase awareness of autism and developmental difficulties, providing information and resources with an emphasis on de-escalation and safety promoting strategies for situations that are directly relevant to policing.
Marymead (Trustees of the Roman Catholic Church for the Archdiocese of Canberra & Goulburn)	Autism Centre ACT	Funding will support Marymead's Autism Centre to continue providing strengths-based, person-centred services developed by experts for individuals, families and carers living with Autism Spectrum Disorder (ASD) in the ACT. The services include new diagnosis information, linkage and referral to other supports, information and education, and autism-specific support for NDIS planning. Marymead will also develop and deliver workshops, support groups, a monthly newsletter and an ASD library with a wide range of all-age resources.
Marymead (Trustees of the Roman Catholic Church for the	Kids' Companions Program	Kids' Companions provides social support, mentoring, participant-driven peer-based activities and projects for children and young people with a disability (who are not eligible for NDIS plans), their siblings, and young people who care for someone with a disability (including psycho social disability). The Kids Companion program holds

Archdiocese of Canberra & Goulburn)		two weekly sessions, monthly community days, and special interest activity days during the school holidays.
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**Table 5 - Information Linkages and Capacity Building – 2017 – 2018 Round 2 ILC Jurisdictional Grants NSW**

Organisation	Project Title	Project Description
Assisted Community Living Limited	Gig Buddies Sydney	Gig Buddies pairs adults with mild to moderate learning disabilities and/or autism with volunteers to regularly attend events or 'gigs', increasing social and community participation. This project expands the successful Gig Buddies program to regional areas of NSW and expands the capacity of the project within Sydney. Funding will be directed towards establishing new partnerships with regional organisations to deliver the Gig Buddies program including the provision of training, support and database and website customisation.
Autism Queensland Limited	Capacity Building in Aboriginal and Torres Strait Islander Communities	This project aims to increase awareness of autism and related disabilities in Aboriginal and Torres Strait Islander Communities in north and north-west NSW. An Indigenous Liaison Worker will coordinate a suite of awareness raising activities in local communities, including community forums, information sessions, events hosted by Aboriginal Councils and community groups and workshops for local service providers and community agencies. The Indigenous Liaison Worker will also support community groups to develop targeted plans to engage children and young adults with autism and design and deliver inclusive community-based activities.
Autism Queensland Limited	Talk To Learn Autism Group	This project will provide parents and carers of children with autism or social-communication and behavioural challenges with access to information, links to community activities and practical support to enhance their child's skills and reduce disruptive behaviours. Funding is directed to two groups facilitated by autism experts, available 40 weeks per year for children 0-6 years and 7-12 years in Inverell, Tenterfield, Moree, Narrabri, and Armidale. The parent-child groups will run for two hours, supporting up to 50 families.
Dare Disability Support Limited	Lost Business	The Lost Business initiative will focus on businesses in the Nepean Blue Mountains region of New South Wales, raising disability awareness and demonstrating the economic and social value in meeting the needs of people with a disability. Building greater business understanding and experience is anticipated to lead towards greater

		<p>confidence of people with disability to use local services.</p> <p>The multifaceted program, initially focusing on the needs of adults with an intellectual disability or Autism, includes:</p> <ul style="list-style-type: none"> <li>• training and creation of resources to assist owners and employees;</li> <li>• the creation of a Business Ambassadors scheme;</li> <li>• distribution of inclusion awards;</li> <li>• published audit self-assessed checklists; and</li> <li>• development of a mystery shopper program.</li> </ul> <p>The project aims to benefit the 5,000 people in the Blue Mountains region that self-report disability.</p>
The University of Wollongong	Establishing a Community of Practice	<p>This project will establish a Community of Practice (CoP) to bring together individuals on the autism spectrum, families, and community members to identify current needs and to develop a model of practice that supports self-determination for individuals and families in rural communities.</p> <p>The model will include information provision and strategies for skill building for individuals and their families. The CoP will involve 20-30 individuals, however the resources created from this will benefit much larger numbers.</p>
MacKillop Family Services Limited	The NDIS in the back o' Bourke	<p>This project provides direct assistance to support people with disability, particularly people of Aboriginal and Torres Strait Islander background, in eight rural and remote Western NSW towns. Local needs, circumstances and conditions will be addressed for up to 100 people with disability. Specifically, the program will:</p> <ul style="list-style-type: none"> <li>• Establish weekly parent support groups, community meetings and community hubs in each town to link families to mainstream services and disability supports to meet the needs of their child, whether eligible for NDIS plans or not.</li> <li>• Deliver tele-practice, to link people with disabilities to mainstream services.</li> </ul>
The Deaf Society	Information for Families of Children with Hearing Loss	<p>A co-designed website will be developed with live chat, telephone and face-to-face information and referral services. The project will also coordinate a parent peer mentoring program to provide psychosocial support to parents coming to terms with their child's diagnosis. 100 unique visitors are expected to the website each month and 40 families are expected to be matched with parent mentors each year.</p>

**Table 6 - Information Linkages and Capacity Building – 2017 – 2018 Round 2 ILC Jurisdictional Grants South Australia**

Organisation	Project Title	Project Description
Autism Association Of South Australia	Community InfoLink	An 'InfoLine' phone service currently supports on average 530 calls per month, providing non-clinical information on a range of topics to anyone within the South Australian autism community. This project will transition all knowledge and information delivered via the info-line into an online resource, including webinar recordings, videos, Autism Spectrum Disorder stories, a glossary, FAQ's and more. This online resource will be co-designed with current & future users, aiming to identify common needs and test solutions. This project will increase general autism-related knowledge and self-determination capabilities within the SA community, leading to improved access to and comprehension of information.
Autism Association of South Australia	Autism Friendly App	This project establishes and populates an App which maps safe, autism-friendly spaces, activities, businesses and services to assist individuals with autism or their supporters to plan outings and participate in mainstream activities. The content population and maintenance of this app will eventually be managed by people with lived experience of autism via crowd-sourcing, volunteer inputs and technical supervision.
Puddles Aquatics Pty Ltd.	Puddles Aquatics	A specialist learn-to-swim program designed for children with autism and other special needs will support the transition of about 150 children across 20 swim schools into mainstream lessons. Specially trained Puddles Instructors will facilitate 30 minute weekly sessions, using a variety of proven strategies and techniques to help children with special needs learn water safety, swimming skills, and to grow in strength and confidence.
The Brain Injury Network of South Australia Inc.	So-Connect	So-Connect is a series of information and awareness sessions for people with cognitive disability including acquired brain injury, Autism spectrum disorder, global developmental delay, intellectual disability, and mental health disorders such as anxiety and depression. The project will focus on individuals who are not likely to receive NDIA plans. Funding is directed to deliver 8 ten-week programs in two regional and six metropolitan locations in SA. The program aims to increase awareness of and connection to mainstream supports such as education, employment and activity organisations. The program also engages previous participants as mentors to increase their confidence and build and develop individual skills.

**Table 7 - Information Linkages and Capacity Building – 2017 – 2018 Round 2 ILC National Readiness Grants**

Organisation	Project Title	Project Description
Amaze Incorporated	Integrated Autism Information and Support Service	The multichannel Autism Information and Support Service provides free, independent, accessible, evidence-based autism information and support for people with autism, families and carers. The content will include diagnosis advice, service information and referrals to community and peer support. The service will be trialled in Victoria with an intention for national scale up.
Autism Queensland Limited	Steppin Up, Steppin Out	Steppin' Up, Steppin' Out will provide autism specific information, community linkages and service referrals for young people with autism, their parents, carers, family and community. This pilot will be rolled-out across Queensland and the Northern Territory over two years and will inform national service delivery in the future. Project activities include 'Yarn Ups' for impacted individuals, a suite of workshops for community and local service providers, and the establishment of key information and referral channels.