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Autism Spectrum Disorder

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by Lenny Roth

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Autism Spectrum Disorder

by

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SUMMARY

The growing number of children diagnosed with Autism Spectrum Disorder (ASD) is an issue of concern both in Australia and overseas. This concern is reflected in the 2008 resolution of the United Nations General Assembly for a World Autism Awareness Day (held on 2 April). More detailed concerns have been outlined in recent parliamentary debates here and elsewhere.

Description

ASD is a developmental disorder that emerges in early childhood and is characterised by impairments in social interaction and communication, and restricted and repetitive behaviour and interests. As indicated by the word “spectrum”, the nature and severity of ASD and its impact on levels of functioning can vary widely from one person to another. The disorder is much more common in males than females. The causes of ASD are not yet clear but it appears that it is caused by a combination of genetic and other risk factors. The diagnostic criteria for ASDs are outlined in American Psychiatric Association’s *Diagnostic Statistical Manual of Mental Disorders* (DSM) and in the World Health Organization’s *International Classification of Diseases*. On 17 May 2013, a new edition of the DSM (DSM-5) was released which contains major changes to the criteria including replacing a number of distinct ASD disorders with one disorder (ASD). Diagnosis of ASD is based on behavioural observation, commonly by a developmental assessment team.

Prevalence

A 2006 report was the first study to estimate prevalence rates of children with ASD across Australia. The study made different estimates based on different data sources. Based on Centrelink data, it estimated a prevalence rate of ASD of 62.5 per 10,000 (or one in 160) for 6-12 year old children. The Chairperson of the Australian Advisory Board on ASD said that this finding could be extrapolated to suggest that there could be as many as 125,000 people with ASD in Australia. An ABS report based on data from the 2009 Survey of Ageing, Disability and Carers estimated that 64,600 people in Australia had ASD but noted that this might be an underestimate. The prevalence of ASD in Australia and overseas appears to have increased significantly in recent decades. It is not known to what extent this increase reflects an increasing number of people with ASD or other factors, including an expansion in the diagnostic criteria and an increase in awareness of ASD.

Impacts and costs

Based on the same 2009 survey data, the ABS reported that people with ASD needed assistance with a range of activities: over 40 per cent needed assistance with self-care, around 60 per cent needed assistance with mobility, and over 60 per cent needed assistance with communication, as well as with cognitive or emotional tasks. About one-third of people with ASD needed assistance in these areas on a daily basis. The ABS also reported that people with ASD have significantly lower rates of completing post-school qualifications and participating in the labour force than other people with a disability. Studies have also shown that ASD can have a significant emotional and financial impact on families. A 2011 report estimated that the annual economic costs of ASD in Australia were between \$8.1 billion and \$11.2 billion.

Early intervention programs

There are a range of early intervention programs for children with ASD. These interventions have been classified broadly as: behavioural, developmental, combined, therapy-based and family-based. Reports assessing the evidence base on the effectiveness of the different interventions were published by the Federal Government in 2006 and in 2012. The 2012 report concluded that the evidence base was still very limited, but that high intensity interventions which address the child and family's needs using a behavioural, educational and/or developmental approach have been shown to be the best early interventions. The report assigned research ratings to the different models/programs currently available. The only programs/models that received the "established" rating were Applied Behavioural Analysis and Early Intensive Behavioural Intervention. A number of other programs/models were given an "emerging" or "best practice" rating: e.g. *DIR Floortime* (developmental) and *TEACCH* (combined).

NSW Government initiatives

The NSW Government provides a range of support for people with disabilities (including ASD) through various agencies. NSW Health provides diagnostic and early intervention therapy services. The Department of Family and Community Services provides and funds early intervention services, every-day living support, respite care, and post-school programs. Family and Community Services has introduced several ASD-specific initiatives including: ASD-specific early intervention services, a commitment to provide 1,000 flexible funding packages over five years to assist children with ASD, and the establishment of an ASD specific childcare centre in Western Sydney. The Department of Education and Communities provides learning support in the educational environment. In 2011, Education and Communities noted that it provides support to over 10,000 students with ASD in public schools in NSW, both in regular classes and in 122 specialist ASD support classes.

Federal Government initiatives

In 2008, the Federal Government introduced the Helping Children with Autism (HCWA) Package, supported by funding of over \$190 million over four years. A major element of HCWA is that children who have been diagnosed with an ASD before the age of six can access \$12,000 in early intervention support over two years from a range of authorised providers. Other components of the package include: funding of 40 autism advisors across Australia to provide information for parents after diagnosis; Medicare rebates for diagnosis and visits to allied health professionals, 150 ASD-specific playgroups, professional development for 450 teachers and support staff, and an ASD website. In addition to the HCWA initiatives, the Federal Government has funded six ASD-specific early learning and care centres including one in South-West Sydney.

Gaps in support

A 2010 national report on post-diagnosis support for children with ASD identified a number of gaps in support including: a lack of tailored ASD programs, a need for a transition process that supports families from diagnosis into therapy, a need for detailed information which is localised and personalised, and the need for case management. The report concluded that significant resources were being invested to help families with children with ASD but that there were long waiting lists for allied health services and intensive

treatment services. A similar report in relation to older children and young people and their families also identified a number of gaps in support. In 2011, the Australian Advisory Board on ASD issued a *National Call to Action* which called for action in seven broad areas including diagnosis, early intervention services, education, a comprehensive and integrated support system, an improved range of services for adults, as well as the establishment of a national ASD register and a national research program.

National disability and school funding reforms

The National Disability Insurance Scheme (NDIS) has the potential to greatly improve the lives of people with a disability. This scheme will fund long-term high quality care and support for people with significant disabilities, including ASD. NSW has agreed to establish the full scheme by 1 July 2018 (most other States will also establish the full scheme by July 2018 or July 2019). The first stage of the scheme will be launched in five pilot sites including the Hunter in NSW from July 2013. The Australian Advisory Board on ASD supports the NDIS but has highlighted the importance of considering the distinct aspects of ASD within all elements of the design of the scheme. Another proposed major national reform that could benefit to children with ASD is changes to the school funding model, as recommended in the 2011 Gonski report. NSW has agreed to participate in these school funding reforms.

Initiatives in selected other states

In 2009, the Victorian Government released an Autism State Plan. This Plan was developed in recognition that ASDs are becoming more prevalent and demand on services and support is growing, and that ASDs have particular features that distinguish them from other conditions. The Plan identified six priority areas for the next ten years. The current government in Victoria has said it is committed to the Plan but it may have been superseded by the new State Disability Plan. One of the strategies in the Disability Plan is to provide better support for people with ASD. In 2011, the Queensland Government said that it was in the process of developing an ASD plan but no such plan has been released. In Queensland, ASD-specific initiatives include an Early Intervention Initiative and increased funding for speech pathologists in schools.

Initiatives in selected other countries

In April 2008, the Welsh Government published an ASD Strategic Action Plan. This was believed to be the first national ASD strategy in the world. Since then, all other UK jurisdictions have developed an ASD Strategy. The strategies in two jurisdictions were developed in order to comply with new legislative provisions. In the US, the *Combating Autism Act 2006* authorised expanded federal activities in relation to autism research, prevention, treatment, and education, and was supported by funding of almost \$1 billion over five years. Two initiatives are expanded training programs for health professionals, and funding for States to develop ASD Plans. A 2011 report on ASD services in nine States noted several issues (including gaps in the evidence base) as well as promising practices. The States agreed on the need to develop a broader and more intensive range of services designed for discrete age groups.

1. INTRODUCTION

The growing number of children diagnosed with Autism Spectrum Disorder (ASD) is an issue of concern both in Australia and overseas. This concern is reflected in the January 2008 resolution of the United Nations General Assembly for a World Autism Awareness Day (which is held annually on 2 April).¹ The General Assembly stated that it was:

Deeply concerned by the prevalence and high rate of autism in children in all regions of the world and the consequent development challenges to long-term health care, education, training and intervention programmes undertaken by Governments, non-governmental organizations and the private sector, as well as its tremendous impact on children, their families, communities and societies.

More detailed concerns about ASD have been outlined in parliamentary debates here and elsewhere.² In NSW parliamentary debates in connection with Autism Awareness Day 2012, the issues raised included: long waiting lists for diagnosis of ASD in the public health system; the importance of early intervention services; the cost of these services for families (\$30,000); problems accessing services in regional areas; the difficulties schools are facing; and the need for interventions to continue into adulthood.

This paper begins by describing ASD, its prevalence and impacts. Next, it refers to the different types of early intervention programs and presents evidence on their effectiveness. The paper then looks at ASD-specific policy initiatives being pursued by the NSW and Federal Governments. The next section outlines gaps in the support system as identified in some recent reports. The following section provides an overview of the proposed national disability insurance scheme and the national school funding reforms. Finally, the paper looks at ASD-specific initiatives in two other States and in the UK and US.³

2. DESCRIPTION

2.1 Main features

ASD is a developmental disorder that emerges in early childhood and is characterised by impairments in social interaction and communication, and restricted and repetitive behaviour and interests. Previously, the term ASD was used to describe a group of developmental disorders but it is now conceptualised as being a single disorder with different levels of severity. As indicated by the word “spectrum”, the nature and severity of ASD and its impact

¹ United Nations General Assembly, [World Autism Awareness Day](#), Resolution adopted by the General Assembly, No. 62/139, 21 January 2008

² See [NSW Parliamentary Debates \(LA\)](#), 28 March 2012; [Commonwealth Parliamentary Debates \(HR\)](#), 28 May 2012, [UK Parliamentary Debates \(HC\)](#), 20 November 2012

³ For further reading on ASD in an Australian context, see Australian Government, Raising Children Network, [Children with Autism Spectrum Disorder](#), [Online]; and B O'Reilly and K Wicks, *The Australian Autism Handbook*, 2nd edition, Jane Curry Publishing, 2013

on levels of functioning can vary widely from one person to another. Many people with ASD also have an intellectual disability, sensory impairments, and/or motor skill deficiencies.⁴ Because of their limitations, it is common for people with ASD to display challenging behaviours such as aggression, tantrums and self-injury.⁵ The disorder is much more prevalent in males than in females.⁶ The causes of ASD are not yet clear but it appears that the disorder is caused by a combination of genetic and other risk factors.⁷

2.2 Diagnostic criteria

The diagnostic criteria for ASD are outlined in American Psychiatric Association's *Diagnostic Statistical Manual of Mental Disorders* (DSM), and in the World Health Organization's *International Classification of Diseases*. This section focuses on the DSM, which is more commonly used in Australia.⁸

Autism was included in the DSM for the first time in 1980, when "infantile autism" was listed in DSM-III as a separate diagnostic category.⁹ It was listed as one of two Pervasive Developmental Disorders (PDDs); the other being Pervasive Developmental Disorder – Not Otherwise Specified (PDD – NOS). In 1988, there was a major revision of DSM-III. "Autistic disorder" became the primary diagnosis within the PDDs category, and the diagnostic criteria were greatly expanded. The second category remained PDD – NOS.

When DSM-IV was introduced in 1994, the types of PDD were expanded to five: Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and PDD-NOS. These disorders often came to be referred to as ASDs, although commonly when the term ASD was used, it did not refer to Rett's Disorder and Childhood Disintegrative Disorder (much rarer disorders). DSM-IV was revised in 2000 but there were no major changes for PDDs. The diagnostic criteria in DSM-IV related to three core areas of impairment: social interaction, communication, and restricted repetitive behaviour and interests.¹⁰ Within each of these areas, DSM-IV listed four symptoms. In brief, the diagnostic criteria for the three main types of PDD were:

- Autistic disorder: Presence of at least six symptoms, including at least two in the area of social interaction, one in communication, and one in behaviour; and these symptoms were present before the age of three.

⁴ Matson and Sturmey, *International Handbook of Autism and Pervasive Developmental Disorders*, Springer, 2011, Ch4;Ch11.

⁵ Matson and Sturmey, note 4, Ch15 and Ch26

⁶ See S Baron-Cohen, '[Why are autism spectrum conditions more prevalent in males?](#)' (2011) 9(6) PLOS Biology e1001081 [Online]

⁷ See A Whitehouse and F Stanley, '[Is Autism One or Multiple Disorders](#)', (2013) 198(6) *Medical Journal of Australia* 302; and See B O'Reilly and K Wicks, note 3, Ch3

⁸ The International Classification of Diseases can be found [here](#).

⁹ The information in this paragraph is taken from J Irwin et al, 'History and Evolution of the Autism Spectrum Disorders', Chapter 1 in J Matson and P Sturmey, note 4, p3

¹⁰ See this [extract](#) of DSM IV criteria on the Raising Children Network website.

- Asperger's disorder: Presence of at least two symptoms in the area of social interaction, and one in behaviour. However, there is no significant general delay in language, and there is no significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour, and curiosity about the environment.
- PDD-NOS: A severe and pervasive impairment in one or more of the three areas but the criteria are not met for a specific PDD. For example, this includes presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomology, or sub-threshold symptomology, or all of these.

DSM-5 was released on 17 May 2013 and introduces major changes to the diagnostic criteria. These changes (which were approved by the Association in December 2012), were outlined in a February 2013 article:

The proposed criteria for the DSM-5 involve one central diagnosis—autism spectrum disorder (ASD)—that will replace the different subtypes defined by the DSM-IV...The diagnosis of Rett syndrome will no longer be included in the DSM. The ASD diagnosis will be accompanied by the indication of the level of symptom severity (on a 3-point scale ranging from “requiring support” to “requiring very substantial support”) as well as relevant clinical “specifiers,” including language and cognitive ability levels.

Social and communication problems will be melded into one category, “social/communication deficits,” which, together with “fixated interests and repetitive behaviours,” will replace the traditional triad of symptoms (impaired social reciprocity, impaired language/communication, and restricted and repetitive pattern of interests/activities) that has been in use since autism (childhood autism) first found a home in DSM-III...

Unusual sensitivity to sensory stimuli, a clinical feature of autism that was not listed in the previous criteria, will now be included as a specification of the behaviours that can be coded in the “fixated interests and repetitive behaviours” domain.

The diagnostic criterion of onset before 36 months is replaced with a more “open” definition, stating that “Symptoms must be present in early childhood, but may not become fully manifest until social demands exceed limited capacities.”¹¹

DSM-5 also introduces a new diagnosis “Social Communication Disorder”, within the category of Language Impairments. Persons with fixated interests and repetitive behaviours will be excluded from this diagnosis.¹²

¹¹ G Vivanti et al, '[Towards the DSM V Criteria for Autism: Clinical, Cultural and Research Implications](#)', (2013) *Australian Psychologist*, [Online], 14 February 2013. See also American Psychiatric Association, [Autism Spectrum Disorder](#), Fact Sheet, 2013;

¹² G Vivanti et al, note 11.

The changes have been controversial. It has been argued that DSM-5 represents a narrowing of the criteria, meaning that some children (those with milder symptoms) may not be diagnosed with ASD and may therefore miss out on government support.¹³ The first DSM-5 field trial indicated that “only 5-10% of people currently captured within the pervasive developmental disorders spectrum will no longer meet the criteria for ASD”.¹⁴ However, a study by Autism Spectrum Australia (Aspect) indicated a higher proportion who would not meet the new criteria. As reported in *The Australian* on 3 September 2012:

Aspect’s study, the first of its kind to be done in Australia, compared how 132 Australian children diagnosed with autism would have fared had they been assessed under the DSM-5. The results showed 23.5 per cent failed to meet the new criteria, which will require children to exhibit at least five out of a possible seven symptoms, instead of three as at present.¹⁵

2.3 Diagnostic process

There is no biological test for ASD. Diagnosis is based on behavioural observations. Most children are diagnosed in early childhood but some children are not diagnosed until later, as their social and behavioural differences may only become more obvious when they are at primary, or even secondary, school.¹⁶ The diagnostic process for ASD has been described as follows:

There is evidence that children with ASD can be reliably diagnosed by the age of 2 years, and general agreement that they can demonstrate recognisable symptoms in their first year of life. However, the average age of diagnosis is around 3 years. The assessment can use either the [DSM or ICD] criteria. In Australia the ADOS (Autism Diagnostic Observation Schedule) and the ADI (Autism Diagnostic Interview) are increasingly used as diagnostic tools...

The process is necessarily fairly complex. It can be a long and arduous one for child and family, whether they visit a private psychologist or speech therapist, or wait for a developmental paediatrician in a public hospital.

The methods used in the public health system to arrive at a diagnosis vary between states...In New South Wales, the family collects reports on the child from a number of sources (for example, child care centres, psychologists, using a questionnaire supplied by the diagnostic unit). This information is analysed by a paediatrician before the child is seen by a specialist. The child is then observed by the developmental assessment team for three or four hours and a diagnosis is supplied to the parents on the same day. Only in very complex cases, or in cases where the diagnosis is unclear, do follow-up visits occur.¹⁷

¹³ G Vivanti et al, note 11

¹⁴ G Vivanti et al, note 11

¹⁵ A Cresswell, ‘Autism diagnosis rules to change’, *The Australian*, 3 September 2012, p3. See also S Parnell, ‘Redefining the Spectrum’, *The Australian*, 4 December 2012, p11

¹⁶ Raising Children Network, ‘[Later ASD Diagnosis: older children and teenagers](#)’, [Online]

¹⁷ K Valentine et al, [Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers](#), Occasional Paper No. 35, Department of Families, Housing, Community Services and Indigenous Affairs, 2010, p35

3. PREVALENCE

3.1 Prevalence rates in Australia

Wray et al report (2006): In 2006, a research group led by paediatrician, Dr John Wray, and paediatric epidemiologist, Dr Katrina Williams, completed the first study to estimate prevalence rates of children with ASD across Australia.¹⁸ The study, which considered different data sources, made these findings:

The 2005 Centrelink data provides an estimated prevalence of autism spectrum disorders in Australia for 6-12 year olds of 62.5 per 10,000. At the current time, Centrelink provides the most comprehensive single source of National information about the number of individuals seeking funding with a diagnosis of Autism or Asperger Disorder in Australia. However, this data is incomplete in relation to individuals aged between 13 and 16 years with autism spectrum disorders and provides no information about individuals with PDD-NOS. Using national disability data provided by the Australian Institute of Health and Welfare, and Centrelink data, this study found the prevalence of autism in Australia in 2003-2004 to range from 8.5 to 15.3/10,000 for 0-5 year olds, 12.1 to 35.7/10,000 for 6-12 year olds and 8.3 to 17.4/10,000 for 13 to 16 year olds...According to available State and Territory data, the prevalence of autism in 2003-2004 ranged from 3.6 to 21.9/10,000 for 0-5 year olds, 9.6 to 40.8/10,000 for 6-12 year olds and 4.4 to 24.3/10,000 for 13-16 year olds.¹⁹

The Chairperson of the Australian Advisory Board on Autism Spectrum Disorders, which commissioned the prevalence study, presented an overview report that explained the study's findings as follows:

There was a considerable degree of variation in prevalence figures from these different sources of data, however, using the Commonwealth Government's own Centrelink data, the core finding is that there is an estimated prevalence of autism spectrum disorders across Australia of 62.5 per 10,000 for 6-12 year old children. This means there is one child with an ASD on average in every 160 children in this age group which represents 10,625 children aged between 6 and 12 years with an ASD in Australia.²⁰

He also noted that this finding "could be extrapolated to suggest that...there could be as many as 125,000 people with ASD in Australia or, expressed in another way, half a million Australians in families affected by ASD".²¹

ABS survey report (2011): In 2011, the Australian Bureau of Statistics estimated the prevalence ASD in Australia based on data from the 2009 Survey

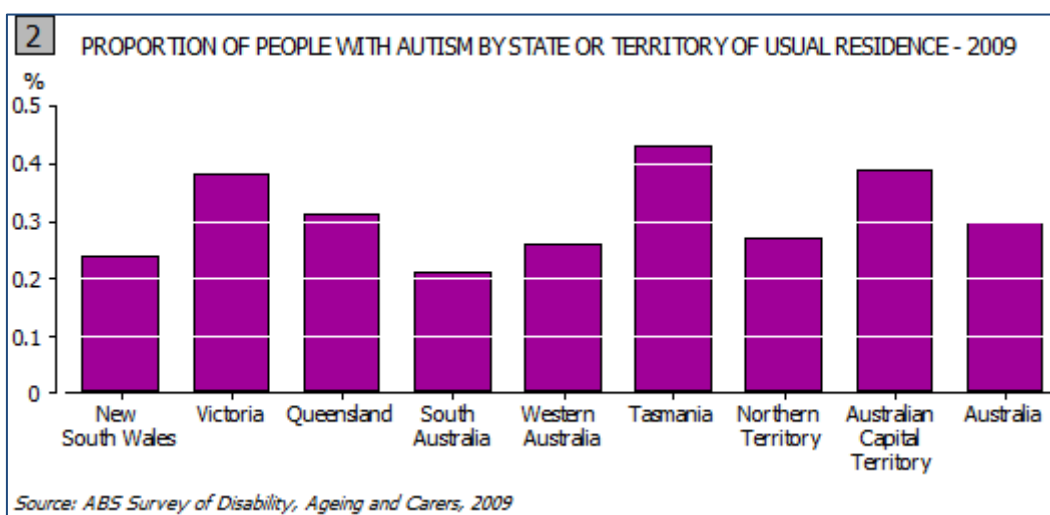
¹⁸ J Wray et al, [The prevalence of autism in Australia: can it be established from existing data?](#), A report prepared for the Australian Advisory Board on Autism Spectrum Disorders, 2006

¹⁹ J Wray et al, note 18, p8

²⁰ A Ford, [The Prevalence of Autism in Australia. An Overview of the Report commissioned by the Australian Advisory Board on Autism Spectrum Disorders](#), 2007

²¹ A Ford, note 20

of Disability, Ageing and Carers.²² It noted that the nature of the survey meant that “the data may underestimate the overall prevalence of autism spectrum disorders”. Based on the survey, it was estimated that 64,600 people in Australia had an ASD (more than double the number reported in the 2003 survey of Disability, Ageing and Carers). ASD was much more common in males (72%) than females (18%). The report noted that there was “considerable variation in the prevalence of autism across age groups, with a marked drop off in prevalence in late teens”. Prevalence rates by State were shown as follows:



3.2 International prevalence rates

A 2011 paper reviewed 27 studies on the prevalence of ASD, published in eight countries since 1999.²³ The range of ASD prevalence rates in these studies was from 30 to 181 per 10,000. The mean rate was 70 per 10,000 (one in 143) and this was considered to be the best estimate of the prevalence of ASD. One of the studies reviewed was a 2009 report in the US which (based on 2006 records in 11 monitoring sites in the US) found a prevalence rate of 90 per 10,000 (one in 110) for children aged 8. A more recent US study (based on 2008 records at 14 monitoring sites) found a prevalence rate of 113 in 10,000 (one in 88) for children aged 8.²⁴ These reports cautioned that the prevalence estimates should not be generalised to the US as a whole. A more recent study in the US estimated a much higher rate based on 2011-12 national survey data. The report stated that the prevalence of parent-reported ASD among children aged 6-17 was 2 per cent (one in 50).²⁵ This was also a much higher rate than was found using 2007 national survey data (one in 86).

²² Australian Bureau of Statistics, [Autism in Australia, 2009](#), Cat 4428.0, 27 July 2011

²³ C Campbell et al, 'Prevalence and the controversy', in J Matson and P Sturmey, note 4, p3

²⁴ J Baio et al, [Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008](#), Surveillance Summaries, US Centers for Disease Control and Prevention, 30 March 2012

²⁵ S Blumberg et al, [Changes in Prevalence of Parent-reported Autism Spectrum Disorder in School-aged U.S. Children: 2007 to 2011–2012](#), National Health Statistics Report No. 65, National Center for Health Statistics, 20 March 2013

3.3 Are prevalence rates increasing?

The prevalence of autism/ASD in Australia and overseas appears to have increased significantly in recent decades. There are ongoing debates about whether this trend means that there are more children who are affected by the disorder. Other reasons for the increase in prevalence rates include:

- An expansion in the diagnostic criteria;
- Changes in the methods used to measure prevalence rates;
- Increases in awareness and understanding;
- Lessening in stigma;
- Availability of government assistance specific to children with ASD.²⁶

4. IMPACTS AND COSTS

4.1 Impacts on individuals

Based on data from the 2009 Survey of Disability, Ageing and Carers, the ABS reported on assistance required by people with ASD, and on educational and employment outcomes.²⁷ It noted that people with ASD needed assistance with a range of activities: over 40 per cent needed assistance with self-care, around 60 per cent needed assistance with mobility, and over 60 per cent needed assistance with communication, as well as with cognitive or emotional tasks. About one-third of people with ASD needed assistance in these areas on a daily basis. Of those people with ASD who had finished school, 77 per cent had not completed a post-school qualification. The ABS noted that this was well above the rate for both the rest of the population with a disability (50 per cent) and people with no disability (42 per cent). Similarly, the labour force participation rate for people with ASD (34 per cent) was well below the rate for all people with a disability (54 per cent) and people with no disability (83 per cent).

4.2 Impacts on families

A 2010 Australian report referred to a number of studies looking at the emotional impact of ASD on families, including two Australian studies from the 1990s.²⁸ One of these studies was noted as follows:

An Australian survey of 219 families in Victoria (Sharpley, Bitsika & Efremidis 1997) found that behavioural problems such as throwing tantrums in public places caused parents more stress than the child's cognitive impairment. The child's behaviour limited parents' ability to seek outside help, such as babysitting services. Behaviour was one of the three most stressful factors associated with parenting a child with ASD, the other two being the permanency of the condition and the lack of social support for parents...

²⁶ See K Valentine et al, note 17, 2011; A Whitehouse, [‘Do more children have autism now than before’](#), *The Conversation*, 11 November 2011; and C Campbell et al, note 6

²⁷ ABS, note 22

²⁸ K Valentine et al, note 17, p16-17

The other Australian study was summarised in this way:

A Queensland study (Gray 1997), which interviewed 53 parents in 32 families with children with ASD (32 mothers and 21 fathers), found that many of them believed that normal family life had eluded them. They felt that activities such as the ability to socialise, the emotional interactions among family members, and the everyday things they thought other families did were routinely disrupted by their child's aggressive outbursts. Mothers were more likely than fathers to see their families as abnormal, perhaps because their child's autism impinged more upon their daily activities and they were more likely to see themselves as being held responsible for their child's behaviour.

Caring for children with ASD can also have a major financial impact on families. In addition to healthcare costs, there may be impacts on the capacity of a carer to continue in employment or to maintain the same level of earnings. The Australian Advisory Board on Autism Spectrum Disorders has cited recent research from the United States about these financial impacts:

Families with children with an ASD have more financial problems, provide significant amounts of healthcare coordination (more than 10 hours a week) for their own children, and are more likely to stop or reduce work than families of other groups of children with special needs (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan et al, 2008). Cidav, Marcus and Mandell (2012) found that on average mothers of children with ASD earn 35% less than mothers of children with other health limitations and 56% less than mothers of children with no health limitation.²⁹

4.3 Economic costs

In 2011, Synergies Economic Consulting prepared a report for the AEIOU Foundation on the economic costs of ASD in Australia.³⁰ The review estimated that the annual economic costs of ASD in Australia were between \$8.1 billion (low prevalence) and \$11.2 billion (high prevalence). This range reflected prevalence estimates of between 36.9 and 62.5 per 10,000. The study examined three categories of costs:

- Direct costs: health care, social services, education;
- Other tangible costs: reduction in income from lost employment; and the cost of informal care for adults with ASD;
- Intangible costs (impacts on quality of life - "the burden of disease").

The total direct and other tangible costs were between \$4.2 billion and \$7.3 billion, with the most significant costs arising from reduced employment and the

²⁹ Australian Advisory Board on Autism Spectrum Disorders, [Autism Spectrum Disorders \(ASD\) and the National Disability Insurance Scheme \(NDIS\) – Position Paper](#), August 2012, p4

³⁰ Synergies Economic Consulting, [Economic Costs of Autism Spectrum Disorder in Australia – Updated Study](#), April 2011

cost of informal care for adults with ASD. The burden of disease contributed an additional \$3.9 billion. A number of costs were not included in the study due to a lack of data: e.g. the cost of early intervention programs, and the informal costs of caring for children with ASD (only the costs of caring for adults with ASD were included in the estimates). The report noted therefore that the estimates were likely to understate the full costs of ASD.

5. EARLY INTERVENTION PROGRAMS

5.1 Types of early interventions

In a 2006 report, Jacqueline Roberts and Margot Prior identified the different types of early intervention programs for children with ASD.³¹ These are shown in the Table below: the last five types in the Table were all classified as “educational” interventions, and these were the focus of the review.

Type	Description
Medication	Medications have been used to treat symptoms and co-morbid disorders such as anxiety and ADHD, as well as to increase the likelihood that children will benefit from concurrent interventions.
Complementary and alternative medicine	These include biological treatments (e.g. vitamin supplements, gluten free diets, antibiotics) and non-biological treatments (e.g. auditory integration training, and craniosacral manipulation).
Psychodynamic	These therapies are based on the assumption that autism is the result of emotional damage to the child. These therapies are seldom used today, as there is strong evidence that autism is a developmental and cognitive disorder.
Behavioural	These interventions use learning techniques to teach and increase targeted positive behaviours and reduce or eliminate inappropriate or non-adaptive behaviours. Approaches are evolving but Applied Behavioural Analysis and Discrete Trial Training are the core features of most programs. Early Intensive Behavioural Interventions are behavioural interventions that are comprehensive and intensive. Intensive means one-to-one treatment in which carefully planned learning is provided and reinforced at a high rate by therapists for at least 30 (preferably 40) hours per week, 7 days per week, for at least two years.
Developmental	These interventions focus on the child's ability to form positive, meaningful relationships with other people. Generally, programs aim to promote attention, relating to and interacting with others, experience of a range of feelings, and organised logical thought.

³¹ J Roberts and M Prior, [*A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders*](#), Australian Government Department of Health and Ageing, 2006

Type	Description
Combined	These interventions combine elements of behavioural and developmental models and take account of evolving knowledge about autism and typical development.
Therapy-based	These interventions focus on communication and social skills development (speech pathology) or sensory motor development (occupational therapy). They are generally used in conjunction with other interventions.
Family-based	These interventions provide support to the families of children with autism, including helping them to understand the nature of autism and their child's learning style, providing teaching strategies to help support their child's learning, helping family members to establish their own support networks, and providing information about services and support programs.

5.2 Evaluations of early interventions

2006 report: Roberts and Prior reviewed the research on these different types of early intervention programs for children with ASD.³² Their general findings about the effectiveness of the interventions are outlined below.

Type	General findings
Medication	Some medications have been demonstrated to be somewhat effective for individuals with autism, although careful monitoring is required to measure effects and side effects (e.g. antidepressants and antipsychotics). Some medications have been demonstrated to be ineffective and/or harmful (e.g. Naltrexone)
Complementary and alternative medicine	There is minimal evidence demonstrating the effectiveness of these interventions and considerable evidence demonstrating no effect for some such as Secretin. Potential risks with some treatments may be significant.
Psychodynamic	These therapies are seldom used today, as there is strong evidence that autism is a developmental and cognitive disorder rather than an emotional disorder.
Behavioural	There is universal agreement that behavioural interventions have produced positive outcomes for children with autism that are well supported by research. However, there continues to be controversy about particular interventions and programs, concerns about methodological issues, and differences in the interpretation of research findings.

³² Roberts and Prior, note 31

Type	General findings
Developmental	There is little research evidence to support the effectiveness of developmental interventions for children with autism. Studies have been pre-experimental, have lacked independence, or have been limited by methodological flaws. Further research is required to determine the effectiveness of these interventions. Studies have been done on discrete components of many of the programs such as social, communication, cognitive and parenting outcomes, which show positive results.
Combined	The results of a small number of studies have indicated positive outcomes for children who access the <i>TEACCH</i> program. However, there is a need for larger, systematic and controlled studies to be conducted by independent researchers in order to evaluate the immediate and long-term outcomes of the program. Long term outcomes of the <i>LEAP</i> (comprehensive pre-school) program are currently being evaluated however independent evaluation is required to determine effectiveness.
Therapy-based	Some research has examined the effectiveness of communication focused interventions with mixed results. Although positive outcomes have been reported for some communication based interventions, there is a lack of large, comprehensive, and well controlled studies. Research is needed to investigate the type and extent of the sensory characteristics of autism and interventions designed to manage these.
Family-based	A small number of studies involving family support programs have yielded positive outcomes for both children with autism and their families. However, there is a need for further research involving large controlled studies to replicate and extend these findings.

The report also noted that effective programs tended to contain a number of key elements, such as providing an autism-specific curriculum content focusing on attention, compliance, imitation, language and social skills.³³ The report then emphasised the need to account for individual variation, concluding:

...there is no one program that will suit all children with autism and their families. Research suggests that there are substantial short and long term benefits from early, intensive, family-based treatment programs, whatever their theoretical basis, so long as these are appropriately adapted to the child's pattern of strengths and weaknesses and take account of family circumstances.³⁴

2012 update report: In a 2012 report, a research team including Roberts and Prior presented an update of the research literature on the effectiveness of early

³³ Roberts and Prior, note 31, p80-82

³⁴ Roberts and Prior, note 31, p82

intervention programs.³⁵ The report essentially supported the findings of the earlier report in relation to the different types of intervention. In summary, it commented that the evidence base was still very limited and then stated:

Nonetheless, high intensity interventions which address the child and family's needs using a behavioural, educational and/or developmental approach have been shown to be the best of currently available early interventions. In addition, a few interventions have now been proven to be ineffective.³⁶

The 2012 report also assigned research ratings to models/programs across the different types of intervention, for use in determining the eligibility of programs for Federal Government funding.³⁷ Applied Behavioural Analysis and Early Intensive Behavioural Intervention were the only programs/models that received the "established" rating. Many others were given an "emerging" or "best practice" rating: e.g. *DIR Floortime* (developmental), *TEACCH* (combined), *PECS* (therapy-based) and *Hanen-More than Words* (family-based).

6. NSW GOVERNMENT INITIATIVES

The NSW Government provides a range of services and support to people with disabilities (including those with ASD) through a number of different agencies. The key agencies are NSW Health, the Department of Family and Community Services, and the Department of Education and Communities. This section provides a brief outline of the services and supports provided by these agencies to people with disabilities, with a focus on specific ASD initiatives.

6.1 Health

NSW Health (through local health districts) provides diagnostic and assessment services in some locations for children with potential developmental disabilities.³⁸ In addition, NSW Health also funds a range of other services for children with a disability or special needs:

Across NSW, health funding for services for children with a disability or special needs largely focuses on early intervention. Allied Health services such as speech pathology, occupational therapy, physiotherapy and counselling are provided through both multidisciplinary teams or on a discipline basis, depending on the child's needs. Location, quantum of services available and accessibility vary significantly across NSW Health sites.³⁹

³⁵ M Prior, J Roberts, S Rodger, K Williams & R Sutherland, [A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders](#), Department of Families, Housing, Community Services and Indigenous Affairs, 2011. See also M Prior and J Roberts, [Early Intervention for Children with Autism Spectrum Disorders: 'Guidelines for Good Practice'](#), 2012

³⁶ Roberts, Prior et al, note 35, p60

³⁷ Roberts, Prior et al, note 35, p50ff. See also the research ratings [summary table](#) published by the Department of Families, Housing, Community Services and Indigenous Affairs

³⁸ See the Raising Children Network website [here](#).

³⁹ NSW Government, [Submission to inquiry into the provision of education to students with a](#)

6.2 Family & Community Services

The Department of Family and Community Services provides and funds a range of support services for people with disabilities. These include: early intervention services, accommodation support, everyday living support, respite care, and post-school programs.⁴⁰ These supports are currently being delivered under the *Stronger Together 2* policy, which is a five year plan from 2011 to 2016.⁴¹

In 2010, the Department provided the following information on initiatives targeted at children with ASD:

Between 2007 and 2010, we will have invested over \$17 million to support children and young people with autism and their families through services, projects and activities specifically relating to autism. Initiatives include:

- \$4.8 million over four years for an early childhood intervention package, supporting families and staff in a range of preschool settings
- \$5.9 million over four years for the Helping Troubled Kids Initiative to support young people with autism and challenging behaviour at risk of suspension from school
- \$6.5 million to Autism Spectrum Australia (Aspect) for autism-specific early childhood intervention services, the provision of support networks for young people with autism and their families, the provision of an autism diagnostic service in regional and rural NSW, and the establishment of an early detection and screening service in the Macarthur, Albury and Wagga Wagga areas
- \$117,500 to sponsor autism-related conferences and workshops. This includes a total of \$30,000 support for conferences and activities related to raising the awareness of autism within the community in 2009/10.⁴²

A more recent initiative is the *Stronger Together 2* commitment to create “1,000 flexible funding packages to assist children with autism at a cost of \$21.1 million over five years”.⁴³ In the first year, 187 of these packages were delivered.⁴⁴ The Department has also provided funding for the establishment of an ASD-specific childcare centre in Western Sydney. It reported:

As part of the broader commitment to supporting children with autism spectrum disorder, SDN Children and Family Services received funds to establish SDN

[disability or special needs](#), March 2010, p93

⁴⁰ Department's [website](#); and L Roth, [Government Policy and Services to Support and Include People with Disabilities](#), NSW Parliamentary Research Service, Briefing Paper 1/2007

⁴¹ NSW Government, [Stronger Together: The second phase 2011-2016](#), 2010

⁴² NSW Department of Human Services, [2009/10 Annual Report](#), p71

⁴³ NSW Government, note 41, p23

⁴⁴ NSW Department of Family and Community Services, [Stronger Together 2 Annual Report 2011-12](#), 2012

Beranga as a demonstration, autism specific service that integrates early childhood intervention and mainstream early childhood education. More than 60 families have so far received help. \$1.2 million was allocated for the autism child care service in 2011–12, with a total investment, including \$2 million of capital funding, of \$6.8 million in the first four years to 2013–14.⁴⁵

6.3 Education & Communities

The Department for Education and Communities has responsibility for early childhood education, primary and secondary schools, and vocational education and training. The Department has a number of programs to support children with disabilities and those with learning needs across all of these sectors.

Support programs operating in regular classes in public schools have included the *Learning and Support Program*, and the *Integration Funding Support Program*.⁴⁶ In addition, there are specialist support classes in regular and special schools. In 2011, the Department noted that it provided services to over 10,000 students with ASD in public schools. It stated:

The Department has developed a wide range of services and programs to support students with ASD across New South Wales. In 2011, this includes 122 specialist autism support classes located in regular and special schools. Over 6,400 students with a confirmed diagnosis of autism are enrolled in regular schools and provided with additional support through the Integration Funding Support Program. In addition, specialist teachers support students with autism in regular classes. More than 3,000 students with autism in regional areas across the State are supported through these provisions.⁴⁷

The Department also provides funding to Autism Spectrum Australia (Aspect), a non-government operator of eight independent schools.⁴⁸ Aspect explains that each of these schools consists of classes located at Aspect sites and also a range of satellite classes located in government and Catholic schools.⁴⁹

In March 2012, the NSW Government announced reforms to the provision of support for students with a disability and special needs in public schools. The *Every School, Every Student: Learning and Support* policy, which is primarily funded under a National Partnership Agreement on support for students with disabilities, focuses on five areas of activity.⁵⁰ These include:

- Professional learning for skilled and knowledgeable teachers

⁴⁵ Department of Family and Community Services, [2011/12 Annual Report](#), p37. For more information on the centre, see [SDN Beranga](#) [Online]

⁴⁶ Information on these programs is available on the Department's website [here](#) and [here](#).

⁴⁷ [Memorandum of Understanding between NSW Department of Education and Communities and Autism Spectrum Australia \(Aspect\)](#), November 2011, p3

⁴⁸ Memorandum of Understanding, note 47, p4-5

⁴⁹ Autism Spectrum Australia (Aspect), [Schools for Children with Autism](#), [Online]

⁵⁰ Department of Education and Community Services, [Every School, Every Student: Learning and Support](#), March 2012

- Support for students with disability in regular classrooms
- Special schools as centres of expertise
- Instruments and materials to better understand and meet additional learning and support needs
- Information to support teaching and learning and expert support.⁵¹

7. FEDERAL GOVERNMENT INITIATIVES

The Federal Government provides income and employment support services for people with a disability. It also provides some funding to the NSW Government and non-government organisations to provide disability services. The Federal Government has introduced two ASD-specific initiatives, which are discussed below. The National Disability Insurance Scheme and the proposed changes to the school funding model are discussed in Section 9 of this paper.

7.1 Helping Children with Autism

In October 2007, the Howard Government announced the *Helping Children with Autism* package, to be supported by funding of \$190 million over five years.⁵² In June 2008, the Rudd Government announced a revised *Helping Children with Autism* (HCWA) package with the same level of funding but over four years, and commencing in July 2008.⁵³ The Government noted that this was "the first national initiative to help families deal with this challenging disorder".

A major element of the HCWA initiative is that children who have been diagnosed with an ASD before the age of six can access \$12,000 in early intervention support from a range of authorised providers.⁵⁴ The funding is for up to \$6,000 per year for two years, and can be accessed until the child's seventh birthday. Families who live in an outer regional or remote area may be eligible for a one-off payment of \$2,000 per eligible child to cover additional expenses associated with accessing early intervention services.

Another part of the package was that parents would "be supported by up to 40 new Autism advisors across Australia providing advice, information and practical help following diagnosis".⁵⁵ Other features included:

- Medicare rebates for ASD diagnosis and 20 visits to allied health professionals such as occupational therapists and psychologists for children aged up to 12 years old;

⁵¹ There has been controversy about some of the changes introduced under this policy. See [NSW Parliamentary Debates \(LA\)](#), 27 March 2012, p9,882; and A Patty, '[Schools confront loss of disability funding](#)', *Sydney Morning Herald*, 2 June 2012

⁵² Mal Brough MP, '[Helping Children with Autism](#)', *Media Release*, 3 October 2007

⁵³ Jenny Macklin MP, '[\\$190 million boost for children with autism and their families](#)', *Media Release*, 25 June 2008

⁵⁴ FaCHSIA [Helping Children with Autism](#), [Online]

⁵⁵ J Macklin MP, note 53

- 150 playgroups specifically for families and children with ASDs;
- Professional development for 450 teachers and school staff to support students with ASDs; and
- Workshops and information for parents and carers of pre-school and school aged children with ASDs, including an ASD website.⁵⁶

The 2010/11 federal budget allocated an additional \$29 million over two years to meet increased demand for early intervention services (taking the total funding to \$220 million over four years).⁵⁷ The Gillard Government is continuing to provide funding for the HCWA package. The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) is responsible for most aspects of the package (including early intervention), but some components are administered by the Department of Education, Employment and Workplace Relations, and by the Department of Health and Ageing.⁵⁸

An evaluation of the FaHCSIA components of the HCWA concluded that:

Overall, the available evidence is that the Package has had a positive impact on children and families, with families reporting children have improved social and communication skills and behaviour, and are better prepared for the transition to school. But, reflecting the differences in their ability to access Package services, there are some differences between reported outcomes by family type. Families from regional and remote areas (including the Northern Territory), Indigenous families and families from CALD backgrounds who have lower English proficiency were less likely to report positive outcomes for their children.⁵⁹

The evaluation report made several recommendations to improve the package, and the Department's response supported most of these.⁶⁰

7.2 Early Learning and Care Centres

The Federal Government has also established six ASD-specific Early Learning and Care Centres around Australia.⁶¹ These centres provide "early learning programs and specific support for children aged up to six years with Autism Spectrum Disorder in a long day care setting"; they also "provide parents with support in the care of their children". The centre established in NSW is the KU Marcia Burgess centre in Liverpool, in South-West Sydney, which opened in

⁵⁶ J Macklin MP, note 53

⁵⁷ Jenny Macklin MP, '[Better start for children with a disability](#)', *Media Release*, 10 May 2011

⁵⁸ FaHCSIA has information on its programs [here](#); DEEWR has information on its programs [here](#); and DoHA has information on its programs [here](#).

⁵⁹ ARTD Consultants, [Final Evaluation of the Helping Children with Autism Package \(FaHCSIA components\)](#), Summary Report, FaHCSIA, 27 January 2012, piii

⁶⁰ FaHCSIA, [Helping Children with Autism Evaluation – Recommendations by ARTD – Government Response](#), 2012

⁶¹ FaHCSIA, [Autism Specific Early Learning and Care Centres](#), [Online]

June 2010.⁶² In 2011, this centre supported 37 children aged between three and six years. It was staffed by a team of early childhood educators, a speech therapist, an occupational therapist, child care workers and a researcher. The centre adopted the Early Denver Start Model as its approach to intervention.

An evaluation of this initiative concluded that the model “provides positive outcomes for children and parents” but that it “has proved to be extremely challenging to put into operation in its entirety”.⁶³ The report noted that the centres have had to supplement departmental funding, and that they have not been able to successfully provide all of the components in the guidelines: i.e. early intervention, long day care, and family support. The report also stated that the current model was high cost and that “options for an alternative model that reaches a greater number of children and families will need to be considered”. The Department made some changes to the guidelines but noted that certain issues identified in the report required further consideration.⁶⁴

8. GAPS IN SUPPORT

8.1 National reports on post diagnosis support

Report focusing on young children: In 2010, the Federal Department of Families, Housing, Community Services and Indigenous Affairs published a report on post-diagnosis support for children with ASD.⁶⁵ The report contained a literature review as well as the findings of a study involving interviews with 49 parents of children with ASD aged less than six years old, and ASD service providers in a number of States (including NSW, Queensland, Western Australia and Victoria). Some of the findings were:

- *Diagnosis:* Parents may experience long wait lists for diagnosis. The reasons for the long wait include multidisciplinary assessment processes requiring multiple appointments, and long waiting lists for diagnosticians in the public health service, or eliminating other possible causes. Waiting for a diagnosis can be extremely distressing to parents, especially those who are aware of the importance of early interventions. After diagnosis, there was an expectation the family would contact therapists themselves and make decisions on their appropriateness.
- *Information and support:* A great deal of information on ASD is available, but parents value personalised, specific information about their own child. Clinicians, service providers and families agreed that

⁶² O'Brien Rich Research Group, Evaluation of the Autism Specific Early Learning and Care Centres Initiative, Final Report, FaHCSIA, February 2012, p19-21

⁶³ O'Brien Rich Research Group, note 62, p2

⁶⁴ FaHCSIA, [Autism Specific Early Learning and Care Centres – Recommendations by O'Brien Rich Research Group – Government Response, Action, Timing](#), 2012

⁶⁵ K Valentine et al, [Post Diagnosis support for children with Autism Spectrum Disorder, their families and carers](#), Occasional Paper No. 35, FaHCSIA, 2010

face-to-face personalised information was the best way to assist families in moving from diagnosis to therapy. The priority for most parents is information about appropriate and available therapeutic interventions. However, there was a lot of frustration with service providers not willing to recommend one therapy over another.

- *Treatment:* The costs for families associated with ASD vary. They can include private services for assessment, diagnosis, treatment and case management, home modifications, and nutritional supplements. Many parents find it disabling to feel that they are doing nothing to treat their children's ASD. Waitlist options are therefore very important for those families who do not take up Applied Behavioural Analysis, which can be started immediately after diagnosis if families have sufficient resources. Families with low-income, lone-parent families and families who do not live close to big cities are often not well served by existing services.
- *Informal and peer support:* Families found support from formal services and other family members. Formal support, in the form of support groups facilitated by peak bodies, is an important source of information; and formal support services offered respite as well as improving the behavioural skills of the child. In areas where there were no formal networks, some parents were getting together to create their own.
- *Early education and transition to school:* Families experience a wide range of quality and accessibility of early education and care services. Families may access specialist services as well as a mainstream kindergarten. The decision to choose mainstream school over a special one is problematic for many parents.⁶⁶

The report identified the following gaps in post-diagnosis support:

- There is a lack of tailored ASD-specific programs: there are only few centres that offer a one-stop shop of early intervention;
- There needs to be a transition process that supports families from diagnosis into therapy;
- There is a lack of detailed information (e.g. on treatments) and information needs to be local and personalised;
- Case management was seen as a huge need by families because the information on ASD is overwhelming;
- There is a need for more support groups in urban centres (there are some parent-run groups in Western Sydney);

⁶⁶ K Valentine et al, note 65 , p6-8

- Families need assistance in selecting an appropriate school.⁶⁷

The report also identified promising practices and one of these was the practice in some States of appointing case managers.⁶⁸ In Western Australia, once a family receives a diagnosis they are referred to the Disability Services Commission. The local area coordinator for the Commission then acts as a case manager for the family. In Queensland, if a family contacts Disability Services Queensland, then a similar sort of case management protocol is followed, especially offering options while the family is on the waiting list.

The general conclusion in the report was that:

Significant resources are being invested in helping families with children with ASD. However, these resources are being invested in an environment where there are long waiting lists for allied health services and the intensive treatment services that many parents want their children to receive. The availability of ASD-specific funding may also lead to an increase in diagnosis as awareness of ASD increases among clinicians, service providers and families. Given this, constraints on the supply of treatment services are likely to remain and probably tighten further; therefore strategies to ensure that all families get some form of intervention immediately after diagnosis seems urgent. Innovative methods of delivering treatment services and programs, described throughout this report, may be appropriate models for wider application.⁶⁹

Report focusing on older children and young people: The Department of Families, Housing, Community Services and Indigenous Affairs also published a related report on post-diagnosis support for older children and young people and their families.⁷⁰ This report contained a literature review as well as the findings from interviews of 18 parents of children with ASD aged 11 to 18, and interviews with service providers. The findings included:

- *Vulnerabilities:* The ASD related impairments that adolescents experience include challenging behaviour such as aggression, anxiety, depression, loneliness, and difficulties with school work and peers. Behaviour interventions that worked well in early childhood were often rejected by the adolescent, particularly in the home environment.
- *Late diagnosis:* Most parents had received a diagnosis more than five years ago. As with families of young children, families of older children had no direct links between diagnosis and treatment and parents needed to spend time and resources finding the best course to take.

⁶⁷ K Valentine et al, note 65, p75-77

⁶⁸ K Valentine et al, note 65, p78

⁶⁹ K Valentine et al, note 65, p82

⁷⁰ K Valentine et al, [Post Diagnosis support for children with Autism Spectrum Disorder, their families and carers: older children and young people](#), Occasional Paper No. 35, FaHCSIA, 2010, [the report begins on p107 of the document]

- *Parents' treatment decisions and approach:* Parents' decisions around treatment were influenced by availability and affordability, but also by their views on the role of treatment in family life and the extent to which they should be involved as therapists.
- *Support for siblings:* Four parents said that their children without ASD suffered embarrassment or other problems because of the behaviour of their siblings. However, two parents who had older children who no longer lived at home talked about the great bond the siblings had.
- *Post-school support:* High school can be an especially difficult time for children with ASD and their parents, as the typical turbulence of adolescence is compounded by the challenges of ASD. Transitioning from high school also often appears to be problematic.
- *Information and service gaps:* There is no authoritative Australian website that gives information on therapies, funding and support agencies in each State for older children and young people. Information about and access to a range of services was often difficult to find.⁷¹

The report identified a number of gaps in services including:

- There needs to be support for adolescents with ASD, including intensive multidisciplinary behaviour intervention programs;
- Families with complex needs require case management services;
- Life skills training should be offered to students from junior high school and extend to job training opportunities;
- Access needs to be provided to information which is aimed specifically at adolescents aged 11 years and over;
- There needs to be development of an ongoing package of therapy for adolescents similar to Helping Children with Autism initiative.⁷²

8.2 Australian Advisory Board Position Paper

The Australian Advisory Board on Autism Spectrum Disorders, which is the national peak body representing the autism spectrum community, has released a number of position papers over the years. In April 2011, the Board issued a *National Call to Action*, which "identified a number of critical imperatives for the Autism Spectrum Community".⁷³ This called for action in seven areas:

⁷¹ K Valentine et al, note 70, p112

⁷² K Valentine et al, note 70, p152

⁷³ Australian Advisory Board on Autism Spectrum Disorders, [National Call to Action](#), April 2011

1. Access to timely and affordable diagnosis for both metropolitan and regional Australia that ensures no more than 3 months wait time for diagnosis and also ensures a national benchmark for a multi-disciplinary approach to diagnosis.
2. Establishment of a National ASD Register to ensure the collection of quality data across Australia that ensures accurate profiling of ASDs in Australia at any one point in time and to describe trends over time.
3. Early intervention services for young children (0-7 years) that ensures that every child has access to a minimum 20 hours of ASD-specific intervention per week, a wait period of no more than three months between diagnosis and service provision, and equitable access.
4. Ensuring that every child has access to an educational service that is appropriate to his/her needs; and that are based on sound evidence and quality indicators; and that range from specialised ASD-specific programs to mainstream programs with appropriate adjustments.
5. Development of a comprehensive and integrated system of providing support to families that ensures they have access to a range of models for support and respite; and that ensure that models of support are flexible and responsive to the needs of families.
6. An improved range of services for adults with an ASD that ensures they receive services and support from professionals with training in ASD, and that ensures that they are given every opportunity to have a full and rewarding life, including being part of the workforce.
7. A research program into ASD treatment, intervention and aetiology.

8.3 NSW reports on special needs education

In 2010 and 2012, Legislative Council Committees examined support for students in NSW with special needs.⁷⁴ The reports raised a number of general issues and made many recommendations. Only those issues raised specifically in relation to ASD are outlined here. The 2010 report noted that between 2003 and 2009 the Department of Education had identified a 165 per cent increase in the number of students with ASD.⁷⁵ In this report, the main issue raised was a lack of special education places for children with ASD, and in particular in rural areas.⁷⁶ The report called for the Department of Education to facilitate the provision of satellite autism classes in these areas.

⁷⁴ General Purpose Standing Committee No.2, [The provision of education to students with a disability or special needs](#), July 2010; and Standing Committee on Social Issues, [Transition support for students with additional or complex needs and their families](#), March 2012

⁷⁵ General Purpose Standing Committee No.2, note 74, p20

⁷⁶ General Purpose Standing Committee No.2, note 74, p68-73

The 2012 report noted one ASD organisation's view that decisions about education services for students with ASD were "based more on...resource limitations than on the student's individualised need for educational support and disability-related services".⁷⁷ The report also referred to concerns that many students with ASD were on long term suspensions, excluded from school or on partial enrolments.⁷⁸ The need for more teacher training in disability issues was also raised in submissions by ASD organisations.⁷⁹ These submissions also called for transition planning for children with ASD to start earlier and for post-transition support to continue for longer.⁸⁰

9. NATIONAL DISABILITY AND SCHOOL FUNDING REFORMS

9.1 National Disability Insurance Scheme

The National Disability Insurance Scheme has the potential to greatly improve the lives of people with a disability (including those with ASD). The Federal and State Governments have committed to establishing a NDIS, as recommended in a 2011 report by the Productivity Commission.⁸¹ A NDIS would fund long-term high quality care and support for people with significant disabilities, including people with ASD. Key features include:

- A lifetime approach – funding is long-term and sustainable. People with disability and their carers will have peace of mind that the individualised care and support they receive will change as their needs change.
- Choice and control – people choose how they get support and have control over when, where and how they receive it. For some, there may be the potential to manage their own funding.
- Social and economic participation – people with disability will be supported to live a meaningful life in their community to their full potential.
- Focus on early intervention – the system will have enough resources and will be smart enough to invest in remedial and preventative early intervention instead of just providing support when a family is in crisis.⁸²

The NDIS is to be known as DisabilityCare Australia. NSW has agreed to establish the full scheme in NSW by 1 July 2018 (most other States have also agreed to establish the full scheme by July 2018 or July 2019). In 2019-20, it is estimated that the scheme will cost \$22 billion: the Federal Government will contribute \$11.7 billion (53 per cent) while the States and Territories will provide

⁷⁷ Standing Committee on Social Issues, note 74, p53

⁷⁸ Standing Committee on Social Issues, note 74, p57

⁷⁹ Standing Committee on Social Issues, note 74, p103

⁸⁰ Standing Committee on Social Issues, note 74, p139

⁸¹ Productivity Commission, [Disability Care and Support](#), Final Report, August 2011

⁸² National Disability Insurance Scheme, [Frequently Asked Questions](#), [Online]

the balance (NSW will contribute over \$3.2 billion).⁸³ Currently, funding of disability services is around \$7 billion. The first stage of the scheme will be launched in five pilot sites (including the Hunter in NSW) from July 2013.

The Australian Advisory Board on Autism Spectrum Disorders has expressed support for the NDIS but has stated that “it is critical that the distinct and complex characteristics of ASD are considered within all elements of the design and development of the NDIS”.⁸⁴ In particular, it has called for the development and use of functional assessment tools that are sensitive to the unique characteristics of people with ASD, and ensuring that assessments are administered by practitioners with expertise in ASD.

9.2 National school funding reforms

Major changes to the school funding model also have the potential to assist students with a disability. The Federal Government proposed these reforms following a 2011 report by the Gonski review panel.⁸⁵ Under the reform proposals, which are conditional upon agreement with States and Territories, the Federal Government will provide 65 per cent of the additional funding required to bring schools up to a new Schooling Resource Standard.⁸⁶ This would involve the Federal Government investing an extra \$9.8 billion over six years from 2014-2015. The Schooling Resource Standard will provide a base amount per student with additional loadings for different forms of disadvantage (including for students with a disability). The NSW Government has agreed to participate in these reforms, which means that NSW schools will receive an additional \$5 billion in Federal and State funding.⁸⁷

10. INITIATIVES IN SELECTED OTHER STATES

10.1 Victoria

In May 2009, the Labor Government in Victoria released an Autism State Plan.⁸⁸ This Plan was developed in recognition that “ASDs are becoming more prevalent and demand on services and support is growing” as well as in acknowledgment that “ASDs have particular features that distinguish them from other conditions”.⁸⁹ The Plan identified six priority areas for the next ten years:

1. Make it easier to get support

⁸³ Australian Government, [DisabilityCare Australia: Stronger, Smarter, Fairer](#), , May 2013

⁸⁴ Australian Advisory Board on Autism Spectrum Disorders, [Autism Spectrum Disorders and the National Disability Insurance Scheme](#), Position Paper, August 2012

⁸⁵ D Gonski et al, [Review of Funding for Schooling – Final Report](#), December 2011

⁸⁶ Australian Government, [National Plan for School Improvement](#), May 2013

⁸⁷ NSW Government, [NSW to implement Gonski school funding reforms](#), *Media Release*, 23 April 2013

⁸⁸ Department of Human Services, Department of Education and Early Childhood Development, Autism Victoria, [Autism State Plan](#), May 2009

⁸⁹ Autism State Plan, note 88, p9

2. Strengthen the ASD expertise of the workforce
3. Extend and link key services and supports especially during transition
4. Enhance and provide appropriate educational opportunities
5. Facilitate successful participation in the community
6. Develop a robust evidence base about ASD

The 2009/10 State Budget provided an initial allocation of \$8.3 million over four years towards the Plan.⁹⁰ This included over \$4 million to provide greater access to mental health services to increase the number of children with complex presentations of ASD being assessed, diagnosed and treated; and over \$4 million to improve regional coordination in education and to support teachers to complete postgraduate study in ASD.

In April 2011, the new Minister for Disability Services said that the Coalition Government was committed to the Autism State Plan. However, the Plan may have been superseded by the new State Disability Plan, which was released in December 2012.⁹¹ Outcome 11 in the State Disability Plan is "better targeted and integrated services" and one strategy to achieve this outcome is to "provide better support for people with autism spectrum disorder". Actions for 2013-2014 in relation to this strategy include:

- Provide support to children, adults, families and carers who are dealing with autism spectrum disorder in a more coordinated and complementary approach across government
- Provide training and advice to disability support professionals over two years to better equip them to meet the needs of people with autism, their families and carers
- Use the Department of Education and Early Childhood Development's regional autism spectrum disorder annual implementation plans to support an integrated early years and school approach through identifying regional priority areas such as professional learning and transition support
- Release operational guidelines for child–adolescent mental health services to help improve the assessment and treatment of children, young people and adults with complex presentations of autism spectrum disorder
- Implement and evaluate a new behaviour support service to test an approach that provides more effective and early support for young people with autism who display behaviours of concern, and their families and carers
- Provide training sessions to mental health clinicians across child, youth and adult mental health services that help to increase their knowledge and skills in

⁹⁰ Victorian Government, 2009-10 [Budget papers – Budget Paper No.3](#), p41, p297

⁹¹ Department of Human Services, [Victorian State Disability Plan 2013-2016](#), 2012

assessment, diagnosis and early intervention for autism spectrum disorder and mental illness.⁹²

10.2 Queensland

In September 2011, the Minister for Disability Services, Curtis Pitt, noted a range of initiatives to assist children with ASD and their families.⁹³ An ASD-specific initiative was the \$4.3 million Autism Early Intervention initiative which supported 471 children with ASD and included centre based services, therapy supports and outreach services to rural and remote areas. The Minister also noted that the Government “was developing a planning strategy to work towards statewide coverage of specific autism services for children with autism aged up to six years”. In addition, the Minister said that the Department was “in the process of developing a statewide autism plan”. No plan has yet been published. In April 2012, the new Minister for Disability Services, Tracy Davis, told a parenting conference hosted by AEIOU about the Government’s initiatives to assist children with ASD. The Minister referred to two new initiatives: the \$4 million ParentConnect initiative to assist parents of children with a disability to access the services they need; and a commitment to provide \$9.5 million for speech pathologists in State schools.⁹⁴

11. INITIATIVES IN SELECTED OTHER COUNTRIES

11.1 United Kingdom

Wales: In April 2008, the Welsh Assembly Government published an *Autistic Spectrum Disorder Strategic Action Plan for Wales*.⁹⁵ This was believed to be the first national ASD strategy in the world. The purpose of the Plan was:

...to set a clear direction of travel for the development of services in Wales by ensuring that specific and measurable actions are undertaken and, on the basis of evidence of prevalence and need, commissioning interagency services at local, regional or national levels as appropriate. It also aims to broaden our understanding of ASD and its prevalence in Wales.

The actions outlined in the Plan covered a number of broad areas including:

- Mapping prevalence, needs and services;
- Commissioning services;
- Transitional arrangements;
- Services for adults;

⁹² Department of Human Services, [Victorian State Disability Plan 2013-2016 – Implementation Plan 2013 and 2014](#), p29-30

⁹³ Curtis Pitt MP, [Letter to Mr Neil Laurie – Clerk of the Parliament](#), 22 September 2011

⁹⁴ Tracy Davis MP, [‘Newman supports parents of children with autism’](#), *Media Release*, 21 April 2012

⁹⁵ Welsh Assembly Government [Autistic Spectrum Disorder \(ASD\) Strategic Action Plan for Wales](#), 2008

- Awareness raising, information and training; and
- Resources.

In February 2011, an evaluation report on the foundation phase of the ASD Strategic Action Plan was published and it noted that “significant progress has been made against the actions originally identified” in the Plan.⁹⁶

England: In 2009, as the result of a Private Members Bill, the UK Parliament passed the Autism Act 2009 (UK), which made provision "about meeting the needs of adults with autism spectrum conditions". The Act required the Secretary of State to publish by 1 April 2010 a strategy for meeting the needs of adults in England with autism spectrum conditions; and to issue guidance to local authorities and NHS bodies to secure the implementation of the strategy.

The UK Government stated that the Act "was created in response to increasing evidence that a significant proportion of adults with autism, across the whole autistic spectrum, are excluded both socially and economically". The Government also noted that this was "the first ever piece of legislation designed to address the needs of one specific impairment group: adults with autism". In March 2010, the Government published the *Strategy for adults with autism in England*.⁹⁷ The Government noted that the strategy's focus was on the next three years, after which progress would be reviewed. During these three years, the strategy was focused on these priorities:

- increasing awareness and understanding of autism among frontline professionals
- developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
- improving access for adults with autism to the services and support they need to live independently within the community
- helping adults with autism into work, and
- enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.⁹⁸

In July 2012, the National Audit Office published a report on progress in implementing the strategy.⁹⁹ The report stated:

Considerable progress has been made in the two years since the Strategy was published: 24 of the 56 commitments have been implemented, and action has

⁹⁶ Welsh Assembly Government, [The ASD Strategic Action Plan for Wales \(2008\) – Evaluating the Foundation Phase](#), February 2011, p11

⁹⁷ Department of Health, 'Fulfilling and rewarding lives': The strategy for adults with autism in England', March 2010,

⁹⁸ Department of Health, note 97, p14. In April 2010, the Department published the [first year delivery plan](#) in relation to the Strategy. In December 2010, the Department published [statutory guidance](#) to local authorities and NHS organisations.

⁹⁹ National Audit Office, [Progress in Implementing the 2010 Adult Autism Strategy](#), July 2012

begun in response to most of the remainder...The Department of Health confirmed that it is committed to progressing the outstanding commitments ahead of a review of the Strategy in 2013.¹⁰⁰

Northern Ireland: In 2009, following an independent review of autism services, the Northern Ireland Government published the *ASD Strategic Action Plan 2009-2011*.¹⁰¹ In 2011, the *Autism Act (Northern Ireland) 2011* was passed and it required the Government to develop an Autism Strategy and Action Plan. In December 2012, the Government released for consultation the *Autism Strategy (2013-2020) and Action Plan (2013-2015)*.¹⁰² The draft Strategy outlines strategic priorities in these broad areas:

- Awareness;
- Accessibility;
- Children, Young People and Family;
- Independence / Choice and Control;
- Transitions;
- Employment and Employability;
- Access to Justice;
- Being Part of the Community; and
- Participation and Active Citizenship

Scotland: The Scottish Government released the *Scottish Strategy for Autism* in November 2011.¹⁰³ The Strategy contains 26 recommendations:

Some of the recommendations are about reviewing and consolidating existing practice whilst others are about improving practice in the light of new learning. Some recommendations are directed at ensuring that there is greater clarity about the cost of services in meeting need and the benefits of strategic budget management, whilst others are focussed on cutting waiting lists for diagnosis and improving the diagnostic process itself. Some are about ensuring that the interests of those on the spectrum are appropriately represented in other areas of policy development and delivery, such as learning disability and self-directed support. Yet others concern themselves with training, research and scrutiny – all of which are needed to support change.¹⁰⁴

The strategy is supported by a funding package of £13.4 million over four years, which is being used to:

- fund the recruitment of local autism co-ordinators to provide information, advice and support

¹⁰⁰ National Audit Office, note 99, p4

¹⁰¹ K Maginnis, [Independent Review of Autism Services](#), 2008; Department of Health, Social Services and Public Safety, [ASD Strategic Action Plan 2009-2011](#), June 2009

¹⁰² Department of Health, Social Services and Public Safety, [Autism Strategy \(2013-2020\) and Action Plan \(2013-2015\)](#), December 2012

¹⁰³ Scottish Government, [The Scottish Strategy for Autism](#), 2011

¹⁰⁴ Scottish Government, note 103, p6

- support the Scottish Autism Services Network, which builds competence in the workforce to assist post diagnostic support
- help people access social care services
- create a development fund of £1 million per annum, for which both local and national organisations can apply
- develop new one stop shop drop-in services for people with autism around Scotland.¹⁰⁵

11.2 United States

Federal Government: The *Combating Autism Act 2006* authorised expanded federal activities in relation to autism research, prevention, treatment, and education.¹⁰⁶ The Act was supported by funding of almost \$1 billion over five years. A progress report on the Act up to 2009 concluded (in part):

In the past four years under the provisions of the Combating Autism Act of 2006 (CAA) (P.L. 109-416), significant advances have been made in our understanding of ASD. Notably, reliable estimates of the prevalence of ASD and a clearer picture of both the opportunities and gaps that exist in ASD research and services are now available. With substantial Federal support, researchers continue the crucial task of evaluating interventions that provide lasting, meaningful benefit to people with ASD...

Through intensive surveillance and research efforts, researchers and Federal agencies can also better identify the unmet societal needs surrounding ASD. While the median age for ASD diagnosis (~4.5 years of age) appears to be on the decline, CDC data indicate a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years. With a continued focus on ASD awareness and training, within both the public and healthcare spheres, this critical time gap can be lessened. Increased attention is being given to pinpointing underserved communities where diagnostic and intervention support is in the greatest need... In addition, services and supports programs across several Federal agencies are actively identifying best practices and implementing programs to increase quality of life for people with ASD...¹⁰⁷

In 2011, the Act was extended for a further three years. A 2013 report by the Government Accountability Office outlined the initiatives undertaken by the Department of Health and Human Services agencies under the Act.¹⁰⁸ It noted that these agencies had established some new ASD activities and had

¹⁰⁵ Scottish Government, '[Autism Strategy Launched](#)', *Media Release*, 2 November 2011

¹⁰⁶ See The White House, '[Fact sheet: Combating Autism Act of 2006](#)', [Online]

¹⁰⁷ U.S. Department of Health and Human Services, Office of Autism Research Coordination, '[Report to Congress on Activities Related to Autism Spectrum Disorder and Other Developmental Disabilities Under the Combating Autism Act of 2006 \(FY 2006 – FY 2009\)](#)', December 2010 (Rev. April 2011), p70

¹⁰⁸ Government Accountability Office, '[Combating Autism Act: HHS agencies responded with new and continuing activities, including oversight](#)', February 2013

continued others. The report referred to the following initiatives undertaken by the Health Resources and Services Administration (HRSA):

HRSA expanded two of its pre-existing training programs—the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) and the Developmental-Behavioral Pediatrics (DBP) training programs—through supplemental funding to existing grantees and awards to new grantees...Under the *Combating Autism Act Initiative*, LEND and DBP grantees are required to include an autism component in their training. Among other things, the programs train health care professionals, such as pediatric practitioners, residents, and graduate students, to provide evidence-based services to children with autism and other developmental disabilities and their families; and train specialists to provide comprehensive diagnostic evaluations to address the shortage of professionals who can confirm or rule out an autism diagnosis.

Additionally, HRSA created new autism research programs to fund studies that are intended to advance the current autism knowledge base and lead to improvements in interventions that address the health and well-being of children and adolescents with autism and other developmental disabilities...

HRSA also funded new state implementation and planning grants to implement plans to improve access to comprehensive, coordinated health care and related services for children and youth with autism and other developmental disabilities. Twenty-two states received grants from fiscal years 2008 to 2011 to implement their autism plans. These plans vary by state, but common elements include a focus on partnerships between professionals and families of children and youth with autism, access to a culturally competent family-centered medical home, access to adequate health insurance and financing of services, early and continuous screening for autism and other developmental disabilities, community services organized for easy use by families, and transition services for youth entering adult health care.¹⁰⁹

State Governments: In 2011, the Centres for Medicare and Medicaid Services (CMS) published a report on State services to individuals with ASD.¹¹⁰ The report outlined the current state of ASD-related services in nine representative States. The first part of the report reviewed the progress and challenges encountered by the states involved in the adoption and implementation of evidence-based/promising practices. The second part discussed one promising practice that was identified by each State. The report concluded (in part):

...the study states...share a common commitment to adopting and implementing evidence-based/promising practices in serving children and adults with ASD. In these nine states, significant gains have been made in reducing barriers to screening and diagnosis, including widespread use of standards-based assessment. Still, each state noted continuing shortages and uneven geographic distribution of credentialed practitioners skilled in the diagnosis of

¹⁰⁹ Government Accountability Office, note 108, p6-7. An example of a State ASD Plan is the [Michigan Autism Disorders State Plan](#), December 2012

¹¹⁰ Abt Associates, [Report on State Services to Individuals with Autism Spectrum Disorders](#), Center for Medicaid and Medicare Services, 1 April 2011

ASD. They have found that goals to provide effective ASD treatment to all age groups and to develop comprehensive ASD care systems are still elusive due to gaps in the evidence, limited provider capacity, and funding constraints.

Challenging economic conditions in the study states, combined with the growing demand for ASD LTTS [Long Term Services and Supports], create a potentially favorable context for the integration of standards and evidence-based practices. This is because, in the face of economic challenges, public officials wish to direct limited resources to the most effective services. States report two serious impediments, however: gaps in evidence-based practices that make it difficult for states to provide a complete services continuum; and lack of investment in standardization and evaluation of promising or emerging practices that could produce the outcome data required to establish new evidence-based practices. Gaps in resources are also impacting efforts to implement the existing evidence-based practices on a broad scale...

There is a high degree of concurrence among states regarding the need to build effective systems of support for individuals with ASD across the lifespan. All informants agree that closing the gaps demands a broader and more intensive range of services designed for discrete age groups...¹¹¹

12. CONCLUSION

Governments around the world face a major challenge in providing support to the rising number of people who have been diagnosed with ASD, and improving their life outcomes. The NSW and Federal Governments have introduced a number of ASD-specific initiatives but reports have identified various gaps in support including access to timely diagnosis, a transition process to support families from diagnosis to therapy, funding for intensive early interventions, supports in the education system, and an improved range of supports for adults with ASD. The proposed national disability insurance scheme has the potential to help close these gaps but the design of the scheme is seen as crucial. Proposed reforms to the school funding model may also assist school students with ASD. In Victoria and the UK, governments have developed ASD-specific strategies or action plans to guide reforms. The US Government has funded a number of States to develop ASD Plans, as well as investing in research, public awareness, and expanding training programs for health professionals.

¹¹¹ Abt Associates, note 110, Ch5