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**Post-diagnosis support for children  
with Autism Spectrum Disorder,  
their families and carers**

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WITH BROOKE DINNING AND DENISE THOMPSON

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**Improving the lives of Australians**

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#### *Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers*

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#### *Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers: older children and young people*

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# Contents

<b>Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers</b>	<b>1</b>
<b>Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers: older children and young people</b>	<b>107</b>



# **Post-diagnosis support for children with Autism Spectrum Disorder, their families and carers**

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# Contents

<b>Executive summary</b>	<b>5</b>
<b>1 Introduction</b>	<b>11</b>
1.1 Background	11
<b>2 Literature review</b>	<b>13</b>
2.1 Introduction	13
2.2 Supporting children and families: principles of good practice	14
2.3 The impact of ASD on parents and families	16
2.4 Therapies	17
2.5 Support for parents and families	22
2.6 Families in rural and remote areas	25
2.7 Conclusion	26
<b>3 Helping children with autism</b>	<b>27</b>
<b>4 Methodology</b>	<b>29</b>
4.1 Limitations of the study	31
<b>5 Findings</b>	<b>33</b>
5.1 Diagnosis	33
5.2 Sources, types and nature of information	37
5.3 Treatments and the role of parents	44
5.4 Informal and peer support	59
5.5 Families with complex needs	62
5.6 Prior-to-school education and care, transition to school, and school	65
5.7 Recommendations for change	71
<b>6 Summary and conclusion</b>	<b>75</b>
6.1 Gaps in support	75
6.2 Promising practices	77
6.3 Conclusion	82
<b>Appendixes</b>	
Appendix A: List of commonly used ASD therapies	83
Appendix B: List of websites providing information on ASD	89
Appendix C: Summary of reported support services by state	91
Appendix D: Interview schedules	93
<b>List of shortened forms</b>	<b>95</b>
<b>Endnotes</b>	<b>97</b>
<b>References</b>	<b>99</b>

## List of tables

<b>Table 1:</b>	Sources and helpfulness of social support reported by families with a child with ASD in the UK	24
<b>Table 2:</b>	Primary sources of support reported by families with a child with ASD in Queensland	25
<b>Table 3:</b>	Participant category, by state	30
<b>Table 4:</b>	Age range of children (years)	30
<b>Table 5:</b>	Therapies currently used	30



# Executive summary

## Background

This is the final report of the research project entitled ‘Post-diagnosis support for people with Autism Spectrum Disorder (ASD), their families and carers’. The research was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) as part of the Social Policy Research Services agreements. The project addresses the following questions:

- What do parents and carers of children with ASD perceive as the most effective post-diagnosis support? What do they perceive as ineffective?
- What are the identified service gaps for families with children with ASD?
- What are the international trends in providing treatment and support services for children with ASD and their families?

This report is based on:

- a review of selected literature addressing the experiences of diagnosis, treatment and support for families with children who are diagnosed with ASD. It focuses on the impact of ASD on families, and on their perceptions of the benefits of the treatment received and support models provided.
- interviews with 49 parents, ASD service providers in New South Wales, Queensland, Western Australia and Victoria.

## Literature review

Autism Spectrum Disorder is a neurodevelopment disorder that covers a range of developmental abnormalities, the most common of which is a lack of communication skills and an inability to interact with other people. There has been a considerable increase in diagnoses of ASD in recent years.

There is a lack of scientific evidence on the effectiveness of one therapy over another. This is partly due to the wide variations in how the ASD presents in a child. There is also uncertainty as to the number of hours of intervention each week required (while there is robust evidence that 20 hours a week is effective, the minimum number of hours, below which treatment is ineffective, is uncertain). However, there is substantial evidence that regardless of the severity of the child’s symptoms early intervention can alleviate the severity of some behaviours. These include ASD-specific education plans and environments; generalising new skills; functional communication approaches to challenging behaviours; and support during key transition times such as from preschool classrooms.

Research also indicates that there is controversy over the specific **treatments** and methods that are most effective, but broad agreement on the intervention **strategy** needed, including early identification and individualised plans, both involving and supporting families.

ASD can result in families becoming isolated, with many experiencing little external social support. Mothers in particular with little or no support exhibited higher levels of stress. Many families felt that normal family life had eluded them due to the behaviour of the child, which was often socially inappropriate.

## Methodology

A total of 49 interviews were conducted between August 2008 and May 2009, of which 32 were with parents. We interviewed clinicians in New South Wales, Victoria and Western Australia, and service providers in New South Wales, Victoria and Queensland. Most children discussed at interview (20) were aged 0 to 5 years. Nineteen families were using multiple therapies including speech and occupational therapy (OT), and ten families were using eclectic, multidisciplinary approaches at ASD-specific or disability early intervention centres.

## Findings

### Diagnosis

Many families reported early 'warning signs' of ASD, detected either by family members or early education and care (EEC) teachers. In some cases parental concerns were dismissed by health professionals.

Parents may experience long waits for diagnosis, even while suspecting ASD and being very active in trying to have their suspicions confirmed. The reasons for the long wait include multidisciplinary assessment processes requiring multiple appointments, long waiting lists for diagnosticians in the public health service, or eliminating other possible causes (for example, ear grommets to discount the possibility that the child has hearing problems rather than ASD).

Waiting for diagnosis can be extremely distressing for parents, especially those who are aware of the importance of early interventions. Several families reported not wanting to wait and going privately for diagnosis as they were aware that the window for therapy was limited.

In general there was an expectation that the family would contact therapists themselves and make decisions on their appropriateness. Parents reported feeling information overload while not having enough information on the range and options for therapies. Families reported feeling bewildered and unsure of what to do next.

The dramatic increase in diagnosis of ASD was remarked by a couple of interview participants, and one service provider considered that ASD-specific funding may make diagnosing clinicians more inclined to diagnose ASD than they otherwise would. However, this suggestion was not confirmed by other interview participants.

### Sources of 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 face-to-face personalised information was the best way to assist families in moving from diagnosis through to therapy.

Parents are typically provided with names of and contact details for early intervention and allied health services at diagnosis. Some parents found this useful, while others reported that this forced them to make choices for which they are ill-equipped.

Although parents want information about the natural history of ASD, especially the long-term prospects of their child's health and happiness, 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, and thus leaving it to the parent to make a decision on therapy.

Most parents in our research used the Internet as their primary source of information on ASD, therapies and prognosis.

Most parents received advice about funding options including Carer Allowance and Carer Payment. New funding for ASD from both federal and state governments is welcome, but systems of payment are confusing for both parents and organisations to navigate.

**Treatments and families' role in treatment**

The costs to families associated when a child has ASD vary. They can include private services for assessment, diagnosis, treatment and case management; modifications to the home; travel to treatment settings; and nutritional supplements and food.

The availability of private, expensive ASD-specific therapies such as Applied Behaviour Analysis (ABA) can also increase rather than relieve parents' confusion and anxiety. Many parents find it disabling to feel that they are doing nothing to treat their children's ASD, and empowering to feel that they are actively treating it (indeed, the capacity of ABA to empower parents recurs in our interviews almost as frequently as improvements to children).

Waitlist options are therefore very important for those families who do not take up ABA, which can be started immediately after diagnosis if families have sufficient resources.

When a child is diagnosed with ASD, parents often take on a role as therapist in addition to these roles, either by following a manualised, highly structured program such as ABA, or by incorporating the principles of other treatment models.

Parents are obliged to take on a significant role in their child's treatment by:

- ▶ assessing therapies
- ▶ coordinating treatments and monitoring their child's progress, in consultation with one or more doctors
- ▶ finding and liaising with early education and care services and schools
- ▶ assisting their child to communicate and behave appropriately in public places and at home.

Parents also take on the role of case manager, albeit reluctantly.

In addition, some therapeutic approaches often encourage parents to change the vocabulary they use to communicate with their child, and their response to their children's behaviour, in all their daily interactions. Families who struggle to find appropriate support in one or more of these areas, and those facing additional challenges, find the experience of ASD especially difficult.

ABA is a therapeutic approach that is supported by robust evidence and represents an enormous commitment from parents because of its intensity and costs. It is possible to combine ABA with other approaches; however, many parents have to choose between ABA and another program, and this can add to the difficulties they face in finding, assessing and choosing treatment options.

**Informal and peer support**

Families found support from formal services and other family members, including other siblings of the child with ASD and grandparents.

In areas where there are no formal support networks, some parents are getting together to create their own support networks.

Formal support, in the form of support groups facilitated by peak bodies, is an important source of information and advice. Formal services offered respite as well as improving the behavioural skills of the child.

**Families with complex needs**

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. Children with ASD often have more than one disability, and of our interview sample two partners of the parent being interviewed, and one parent, had been diagnosed with ASD (that is, Asperger's Disorder) themselves, around the same time as the child had.

### **Early education and care and transition to school**

Our interviews indicate that families experience a wide range of quality and accessibility of early education and care (EEC) services. Four parents did not experience good support from mainstream EEC services. Their experiences included the EEC service not fully understanding the needs of a child with ASD, and parents having to try and fund, or find funds to pay for, extra teaching support. However, where EEC services have resources and commitment to accommodate children with ASD, they may also be eligible for assistance for specialist support staff, which can be enormously beneficial for children and families.

Many parents access specialist support through ASD-specific multidisciplinary therapy services such as AEIOU in Queensland or Autism WA, therapy specific services such as ABA, or short courses on early intervention such as Building Blocks run at Autism Spectrum New South Wales. Families may access one of the specialist services as well as a mainstream kindergarten or, as in the case of AEIOU, send their child there for up to 25 hours per week.

Multidisciplinary approaches to early intervention include plans to support transition to school.

The decision to choose mainstream school over a special one is problematic for many parents. Many parents expressed the desire for their child to mix with normal developing children, while other parents were concerned about the potential for bullying and social isolation that could happen in mainstream schools.

### **Recommendations for change**

Parents, service providers and clinicians made recommendations in a range of areas to improve support for children with ASD and their families, including:

- a one-stop shop of federal and state services
- increased availability of allied health services
- more information to general practitioners (GPs) and baby health centres
- the development of information suitable to give parents and friends
- information on teenage years and potential problems
- the central coordination of waiting lists
- access to early intervention
- the details of therapists experienced with ASD
- access to a 1800 number for support
- information on schools
- funding/state funding
- Autism Advisors
- regional and rural support
- service coordination.

## Conclusion

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.



# 1 Introduction

This is the final report of the research project entitled ‘Post-diagnosis support for people with Autism Spectrum Disorder (ASD), their families and carers’. The research was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) as part of the Social Policy Research Services agreements. The project addresses the following questions:

- ▶ What do parents and carers of children with ASD perceive as the most effective post-diagnosis support? What do they perceive as ineffective?
- ▶ What are the identified service gaps for families with children with ASD?
- ▶ What are the international trends in providing treatment and support services for children with ASD and their families?

## 1.1 Background

In late 2007 FaHCSIA presented the following rationale for this research:

Autism Spectrum Disorder (ASD) now affects approximately 1 in 100 children aged 0 to 12 years. However, diagnosis is difficult, with many children not being diagnosed until they are in primary school. This means that many children with ASD, their families and carers, have to come to terms with the child’s condition during the key life-course transition between early childhood and primary education. This decreases a child’s chance of getting the best start in life, as they are more likely to fall behind their peers in the mainstream school environment.

It is generally accepted that early intervention measures (such as supported playgroups, intensive one-on-one therapy, etc) that take place as soon as possible after diagnosis are extremely effective in helping children with ASD get the best start in life and ensure that they can develop their social and academic skills in the quickest possible manner.

There is existing research that focuses on measuring the effectiveness of early intervention measures for children with ASD, but this has mainly focussed on clinical, as opposed to behavioural, approaches. But there has been little attention paid to what approaches parents and carers find most effective for their children. Thus, it appears that there is a need to determine what parents and carers perceive as the most effective early intervention measures for assisting their children with ASD in the immediate post-diagnosis stage.

Such a project would allow FaHCSIA to develop a better understanding of what measures are most effective for children with ASD in the transition between early childhood and primary education. This would in turn allow future policy to target particular services to families and carers of children with ASD, so as to ensure that parents and carers are better able to take the necessary steps in the post-diagnosis stage to allow their children to receive the necessary support during their movement through this key life-course transition.

This report is based on:

- a review of selected literature addressing the experiences of diagnosis, treatment and support for families with children who are diagnosed with ASD. It focuses on the impact of ASD on families, and on their perceptions of the benefits of the treatment received and support models provided.
- interviews with 49 parents, ASD service providers and clinicians in New South Wales, Queensland, Western Australia and Victoria.



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## 2 Literature review

### 2.1 Introduction

ASD is a cluster of developmental disorders that are usually diagnosed around the age of 3 years, although recent changes to diagnostic tests have reduced the age at which a diagnosis can be made to 18 months old. As its name suggests, ASD refers to a spectrum of conditions that range in severity. It is characterised by disturbances in affect and behaviour, impaired social relationships, repetitive and ritualistic behaviour, and delays in speech development. Children with Asperger's Disorder (AS; or what is sometimes known as 'high functioning' autism) typically have fewer impairments in language development. In contrast, children with 'core' or 'classic' autism may never speak. Behavioural disturbances also range in severity but can involve violent rages and aggressive behaviour, poor sleep patterns and self-harm. Children with ASD are often physically healthy but the nature of their disability can have an enormous impact on the day-to-day lives of their families.

The prevalence of ASD is increasing over time, in part because of the broadening of diagnostic categories. Whereas autism was once thought to be relatively rare (4 per 10,000 in 1966), a report based on prevalence data in 2006 suggested a prevalence rate of 62.5 per 10,000 or as many as 125,000 people with ASD in Australia (MacDermott et al. 2006). The website introduced as part of the Helping Children with Autism package (Section 3) states that 1 in 160 Australian children have ASD.

The extent to which it typically co-occurs with intellectual disability is unclear. A survey of the literature on rates of intellectual disability in children with autism (Edelson 2006, p. 52) found that, although there was a consensus in the literature that most children with ASD did have intellectual disability, the evidence did not warrant that conclusion. The studies claiming high rates of intellectual disability tended to be methodologically problematic—either they lacked empirical verification, or presumption of intellectual disability was made on the basis of developmental criteria, not as a result of testing. The author said that the best estimate of the prevalence of intellectual disability among children with ASD, based on recent epidemiological surveys, was 40 to 55 per cent, much less than was usually cited in the literature (Edelson 2006).

Nonetheless, whatever the level of the child's intelligence, the disability can have an enormous impact on the day-to-day lives of their families. Common activities like shopping may be severely curtailed because children are extremely distressed by changed environments. Parents have been known to report feeling acutely embarrassed by their child's behaviour in public places, sensing the disapproval of strangers who interpret behavioural disturbances as bad parenting or naughty behaviour. According to the findings of a research study investigating out-of-home placement tendency among families with 6 to 13 year-old children with disabilities and high support needs (Llewellyn et al. 1996), autism was among the factors most likely to lead families to consider placing their child in out-of-home care. It would appear that the strains autism place on a family are greater than the strains of physical disability. The parents of children with physical disability perceived their child's behaviour to be less troublesome than the parents of children with autism or mental disability; and those parents considering out-of-home placement for their children reported higher demands from the child's medical/health care needs and behaviours, than parents not considering the possibility (Llewellyn et al. 1996).

In recent years the number of children diagnosed with ASD has been rising (Kanne et al. 2008; Koegel, Symon & Koegel 2002; Spreckley & Boyd 2009). It has been suggested that this is not necessarily due to an increase in the actual prevalence of the disability but rather to better diagnosis. It is probably due, at least in part, to better assessment and detection procedures, and expanded classification criteria. Health professionals are now more familiar with ASD, and have a better understanding of developmental disorders and the range of behaviours typical of it. Whatever the cause, increased numbers require additional services if the needs of these children and their families are to be met (Symon 2001, p. 161).

Support for families is often not readily available. Mainstream early education and care (EEC) services (such as preschools and long day care) and schools do not on the whole have the capacity to meet the needs of children with ASD and their families affected. ASD treatment regimes are diverse in orientation, efficacy and availability, which can add to the complexity of the tasks parents face at diagnosis and after diagnosis. Many treatments also require and depend for their efficacy on parents, usually mothers, devoting significant time and other resources to administering them.

Families affected by ASD share experiences in common with the families of children with other disabilities, particularly waiting lists and expenses associated with treatment. However, ASD is characterised by particular challenges for parents.

- Recent years have seen a dramatic increase in the incidence of ASD. This means a high demand for existing services and treatments, as increasing numbers of children and families need them. It also means that diagnosing clinicians and other service providers may have gaps in their knowledge about treatment efficacy and availability of therapies, as ASD was considered relatively rare until relatively recently.
- A range of treatment approaches are available, and there is no consensus on the most effective. Moreover, as ASD is a spectrum of disabilities rather than a single disability, evidence of efficacy for a small group of patients cannot be generalised to evidence of effectiveness for the general population of patients. Speech therapy may be effective for children with delayed language acquisition, but may not be an urgent need for children with high functioning language skills.
- There is broad consensus that the effective treatments are characterised by the involvement of parents in treatment programs, for example, intensive training in rewarding desired behaviours and ignoring undesirable ones. However, these obligations to act as therapists can place additional stresses on parents.
- ASD is often understood by parents and therapists in educational and behavioural, rather than clinical, terms. However, psychological and clinical services may be the only accessible treatment models.

This review incorporates material from the websites listed in Appendix B, and searches of the databases Medline, Embase, Sociological Abstracts, Social Work Abstracts, Web of Science and Google Scholar. Searches were based on the search terms ‘autism spectrum disorder (or Asperger’s or autism)’, ‘treatment (or therapies or diagnosis)’, and ‘stress’, ‘families’, ‘parent perceptions’, and ‘efficacy’. Selected sources were entered into an electronic database (EndNote). Sources describing clinical efficacy were not included.

The following section describes findings on good practice for supporting families affected by disability around the time of diagnosis. Section 2.3 describes the impact of ASD on the family. Section 2.4 reviews the literature on treatment models and the role of parents in supporting or delivering treatments. Section 2.5 summarises what is known about effective support for families affected by ASD and about the gaps in available support. A glossary of commonly used treatments specifically or primarily for ASD, including information on evaluations where available, is included at Appendix A. A list of international and Australian websites that provide information about ASD treatment and support is included at Appendix B.

## 2.2 Supporting children and families: principles of good practice

In 2006 the Australian Government Department of Health and Ageing (DoHA) commissioned research on service provision for children with ASD and their families in Australia. The findings from that research are that effective programs:

- provide an autism-specific curriculum content focusing on attention, compliance, imitation, language and social skills
- address children’s needs for a highly supportive teaching environment
- include specific strategies to promote generalisation of new skills

- address children's need for predictability and routine
- adopt a functional communication approach in addressing challenging behaviours
- support children in their transition from the preschool classroom
- ensure that family members are supported and engaged in a collaborative partnership with professionals involved in the delivery of treatments (Roberts & Prior 2006, p. 14).

Similarly, a recent evaluation of early intervention support for children with ASD in Northern Ireland notes that while there is controversy over the specific **treatments** and methods that are most effective, there is broad agreement on the intervention **strategy** needed:

- early identification from 18 months of age
- individual education plans that match child and family needs
- parent and family training in programs that can be used at home
- supporting families who experience extra stress
- encouraging integration and inclusion in educational institutions, and family and community life (McConkey, Kelly & Cassidy 2007).

In the United Kingdom (UK), the National Autistic Society's National Initiative for Autism: Screening and Assessment recommends that each child is assigned a key worker at diagnosis who would be involved in drawing up an individualised plan of treatments and therapies for the child (National Initiative for Autism: Screening and Assessment 2003).

However, although there is little research on the experiences of Australian families at the time of diagnosis, research from overseas indicates that, more often than not, families' experiences are at odds with these principles. In a paper from a workshop in Sydney, Rita Jordan (2004) pointed out that families often know more about what is happening overseas than in their own country, and that robust, current information is hard for them to find. Research in the UK found that families experienced the process of diagnosis as slow, disorganised and unhelpful, and that very little information or support was provided by the diagnosing clinicians. Parents said they wanted the diagnosis procedure to be quicker and smoother and to have more structure and standardisation. They also said that professionals should be trained both in the knowledge and skills specific to autism, and in interpersonal and communication skills (Osborne & Reed 2008).

Research conducted in 2008 in Western Australia also found that parents emphasise the impact and importance of the family and the need for family-focused information, support and resources, as well as the need for a single information source (MacDermott 2008). Reviews of families' experiences of the diagnosis of disability more generally also indicate the importance of accessible, relevant information. In a study by Tudball et al. (2002), conducted in the inner western suburbs of Sydney, parents of children with disabilities said that there were insufficient links between service providers and insufficient knowledge on the part of each service of what the other services were offering. They said that they wanted fairly brief information on the impairment, possibly in the form of a fact sheet, at diagnosis. They also wanted to be given some sense of optimism and information on peer support groups who could assist in coming to terms with the diagnosis. They reported that during the assessment process the only useful sources of information were other parents. They found that, at that stage, too much information was overwhelming. It was also often out of date and not designed for families because it was too technical. Most service providers relied on verbal rather than printed communication.

The report recommended:

- information for families with a child with disability be provided at a variety of literacy levels so that it is accessible to all family members, and at accessible places (such as public libraries)

- ▶ campaigns to raise general awareness of childhood disabilities be broadcast via radio and television. Parents found that they already needed a level of expertise before they accessed services in order to know what services they required.
- ▶ information about alternative services be made available to parents on the waiting lists, especially about peer support programs and family respite services
- ▶ a single first point of contact be provided to assist families to navigate their way through the service maze, to serve as a mentor as well as an information provider and refer them to appropriate services (Tudball et al. 2002).

A report on the needs of families with children with disability in Australia (Llewelyn et al. 1996) argued that families needed support and therapies that were aligned with the needs of the rest of the family, not just the child with disability. There was a need for service providers to understand the family dynamics, and work with them in providing the therapies and services. A UK study investigating what the parents of children with brain damage felt about service provision (Case 2000) found that they were very unhappy with the attitudes of the professionals treating their children. They experienced the parent–professional relationship as one of conflict rather than cooperation, and the professionals as controlling and domineering experts who were unwilling to address parental concerns such as counselling, the efficacy (or otherwise) of alternative therapies, or the social implications of the child’s differences. By way of contrast, the authors cited contemporary research which has deliberately moved away from the medical model and incorporated notions of integrated care and partnership relationships between parents and the professionals.

In a review of early intervention programs for children living in poverty and children with developmental disabilities, Ramey and Ramey (1998) found that interventions that start early, run for a long period of time and are intensive are more effective than those that do not have those characteristics; that therapies that rely on parent training are less beneficial than those using both parents and therapists; and that therapies that use parents, therapists, school and other avenues are more effective still.

## 2.3 The impact of ASD on parents and families

People with disability and their families often suffer the effects of inadequate support systems. Parents of children with disability frequently report feelings of social isolation, anxiety, depression, loss, loneliness and hopelessness. Parental stressors can have a variety of causes, including difficulty in accepting the disability; difficulty adjusting to the disability, including getting information on appropriate treatments; time management conflicts; and the limited availability of services (Ainbinder et al. 1998).

A study by the Australian Institute of Family Studies, the Families Caring for a Person with a Disability Study (FCPDS) of 1,002 primary carers (Edwards et al. 2008), found that a substantial minority of carers did not have any support or help in caring for the person with disability. Overall, one in five primary carers had no help from anyone else in caring for the person with a disability. They were least likely to receive ‘help with everyday duties’ such as shopping or housework—33 per cent said they didn’t get any help in this area. Fourteen per cent of carers said they had no-one to give them advice. Just under 20 per cent of the carers said they had no-one to talk to about worries and fears about caring, and almost 25 per cent said they had no-one to talk to about worries and fears more generally. Close to one-third of the people being cared for had no-one except their primary carer to help them with self-care, mobility and communication. Moreover, even those carers who did have support sometimes found the support itself could be a cause of conflict and stress. About one-fifth reported that they had disagreements with the other carers or that the other carers disagreed among themselves (Edwards et al. 2008, pp. xiv–xv, 38–40).

Another study (Sanders & Morgan 1997) found that families with children with ASD experienced more stress than families with children with Down syndrome. This is probably due to behavioural problems and the fact that children with ASD can look ‘normal’ so their behaviour is viewed unsympathetically (Sanders, 1997). The study found that the poor sleep patterns of the children with ASD, their aggression and their patterns of self-injury all caused high stress levels. 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 (Sharpley, Bitsika & Efremidis 1997).

A review of the published literature on the relationship between stress and social support for mothers of children with ASD found an association between challenging child characteristics and a mother's inclination to seek social support, with mothers under greater stress being more prone to pursue social support. For mothers of children with autism, informal support appeared to be more of an effective stress buffer than formal support, although mothers of children with challenging behaviour and cognitive limitations did seek formal supports such as respite care (although not necessarily therapies), especially if they were isolated. The cumulative results of several studies showed that mothers who received support had better relationships with their children, and that inadequate levels of social support were the most powerful predictors of depression and anxiety in mothers (Boyd 2002). Gray and Holden (1992) also found that the best predictor of maternal depression in families with a child with ASD was low or no social support for the mother. Indeed, social support was found to be the major inhibitor of depression in mothers of children with ASD.

A Canadian study of 44 parents of children with ASD aged between 2 and 7 years old (Konstantareas & Homatidis 1989a) investigated the connection between symptom severity and parental stress. Mothers were not found to be more stressed than fathers when a child had severe symptoms, despite the fact that mothers are significantly more involved in the day-to-day care of their children than fathers. However, mothers were found to be more stressed than fathers overall. Fathers were most distressed by the child's inability to speak, while mothers were most distressed by visible behaviours like inappropriate crying or giggling, or bizarre bodily movements. Both parents were equally distressed by the child's self-harm. Hyperirritability was also a prime cause of stress for mothers, although not for fathers. Mothers were also more likely than fathers to find older children stressful, possibly because of the child's increased size and strength, or because of the mother's increasing age, or because of worries about what is to happen to the child, or because of the wear and tear of the years of caring. Mothers also reported that the support they received from their husbands was inadequate in such areas as caring for and disciplining children and helping with housework.

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.

A study by the same author of 33 parents (24 mothers and 9 fathers) living in and around Brisbane (Gray 1994) found that the most serious stresses named by parents were lack of normal language, disruptive and violent behaviour, and inappropriate eating, toileting and sexual expression. Parents used a range of coping strategies, including reliance on service agencies, getting support from other family members, reclusiveness and social withdrawal, religion, engaging in activities that would allow them to live as normal a life as possible, and political activism. The study did not find any single coping strategy that was clearly better than any others for helping the parents adjust, but the availability of services and family support appeared to be the most successful coping strategies for many of the parents.

## 2.4 Therapies

In Australia and internationally the prevalence of ASD is increasing, and with this an increase in the number and types of treatments being made available. The clinical efficacy of many of these is uncertain. In their review of the research to identify the most effective models of practice in early intervention of children with ASD, Roberts and Prior (2006) noted that, because autism straddled many different disciplines, professionals needed to adopt a multidimensional framework, not only in its treatment but even in its definition and diagnosis.

That framework should involve people working in different disciplines, and intervention strategies should include all concerned parties—parents, teachers, peers, the person with autism and other professionals. These authors also pointed out that the recent rapid growth in the United States (US) and the UK of parent-training interventions for preschool-age children highlighted the importance of early identification and of the need for well-informed diagnosis and assessment in Australia as well. They stressed the importance of making services available immediately after the child is diagnosed, and of ensuring coordination of diagnosis and service provision, and recommended this as a key goal for policy makers, funders and service providers nationally. They also emphasised the fact that, while there was no evidence that ASD could be cured, there was a great deal of evidence that appropriate interventions could help children with autism develop and learn behaviours that would equip them for life. However, the report also noted a lack of seamless transition for the child in moving on from the early childhood intervention and into the school environment. There was also a tendency for duplication of services, and most services were reported to have long waiting lists (Roberts & Prior 2006, p. 109).

There are few sound scientific studies of what constitutes effective therapy for ASD (Francis 2005). It is important that families have information on treatment availability, efficacy and risk of harm. There are as yet no empirical measures for what constitutes improvement (Matson 2007), but there is a growing literature on the benefits of behavioural intervention, particularly in the early years (Symon 2001, p. 161). Treatment and therapy regimes are described in detail in Appendix A.

Roberts and Prior (2006) classified interventions into three main types:

- biological (both conventional medication, and complementary and alternative medicine, for example, vitamin B6, cranial osteopathy)
- psychodynamic
- educational.

They advised caution in the use of any of the variants of the first type (apart from medication for behaviour modification) on the grounds that there was no evidence of beneficial effects for any of the therapies discussed, and some evidence of harmful effects. Psychodynamic interventions are rarely used today as ASD is no longer understood as an intrapsychic disorder. Their review focused on educational interventions, because individualised education incorporating communication and behavioural strategies are the primary mode of intervention for ASD. Educational interventions themselves are classified according to modality: behavioural, developmental, therapy-based, combined or family-based. Of these, the behaviourally-based Applied Behaviour Analysis (ABA); the combined intervention TEACCH (Treatment and Education of Autistic and Communication related handicapped Children); and the family-based Hanen programs are widely used in Australia, as are generalist developmental disability therapies such as speech therapy.

ABA is one of the most established interventions for ASD and has a particular presence in the Australian context because it appears to be immediately available to parents who can afford it. This distinguishes it from other early intervention and ASD-specific treatments, which can have long waiting lists in the public and even private systems. Multi-treatment or eclectic service centres seem to be highly valued, and may operate at similar intensity to ABA, but these are available only in specific locations. ABA is therefore discussed in detail in this report because of these particularities of availability and cost. ABA is based on work carried out by Dr O Ivar Lovaas at the University of California. ABA works by breaking down activities into discrete learning blocks. The child is shown how to perform the task (for example, brushing hair) and then repeats the action until the activity is completed, at which point the child is rewarded. The program is intensive, requiring a minimum of 20 hours a week. Treatments based on ABA have been shown to be effective, with highly structured one-on-one therapy successful in more than 50 per cent of cases (Mandell, Stahmer & Brodtkin 2007).

However, highly intensive therapy regimes are not always appropriate for treating children with ASD. ABA may not be as effective for children at the lower functioning end of the spectrum, or for older children (Francis 2005; Smith, Groen & Wynn 2000), or in the presence of high levels of parental stress, as high stress levels in the family can undo whatever gains the program has made (McConkey et al. 2007). As well, a recent systematic review of

four clinical trials of the effectiveness of ABA-based programs for preschool children with ASD (Spreckley & Boyd 2009) found that there was inadequate evidence that these programs had better outcomes than standard care. Moreover, intensive ABA treatment is expensive and it is not generally recommended by diagnosing doctors in Australia for that reason (Couper & Sampson 2003). Western Australia is the only Australian jurisdiction to provide partial funding for ABA programs.

Apart from the financial costs, a high frequency of sessions can be very stressful for parents, especially mothers, who are the ones most likely to administer the treatments. Fonagy et al. (2002) noted that 40 hours of input per week per child is unlikely to be available in routine clinical practice, and they recommended further research to find out if similar benefits could result from a less intensive input. More recently, Spreckley and Boyd (2009) noted that a 40 hour a week intervention in the home was no longer being recommended because it was such a major burden for the family. The recommended number of hours had been reduced to 30, although this still made heavy demands on the time of both parents and service providers.

TEACCH was founded by Eric Schopler in the School of Medicine at the University of North Carolina. It builds on the strengths of each individual child and uses visual cues for shaping behaviour. While there have been no large-scale studies of the program, one small-scale controlled trial showed some improvement in preschool-age children (cited in Francis 2005).

Treatments not specifically devised for autism, such as Augmentative and Alternative Communication (AAC), are also used in conjunction with ABA and TEACCH. AAC involves ways of helping people communicate who have difficulties with speech or writing. It includes signing and gesture (which are called unaided systems because they do not need anything extra), and picture charts, books and special computers (aided systems) (ISAAC 2009). These therapies aim to provide alternative communication skills to speech, or to assist with speech, with the aim of reducing frustration and increasing socialisation. Functional Communication Training (FCT) is a behavioural strategy for teaching people with autism to use AAC to get what they want and communicate more generally, instead of engaging in problem behaviour, by using substitutes for the 'messages' underlying the behaviour. It provides positive alternatives to challenging behaviour, such as picture symbols, manual signing and speech-generating devices. FCT is currently considered to be a 'treatment of choice' in the management of challenging behaviours in children with ASD (Roberts & Prior 2006).

Early intervention should teach competencies in social and cognitive abilities, verbal and nonverbal communication skills, and adaptive skills, and aim for the reduction of behavioural difficulties and the generalisation of abilities across multiple environments. There is no proven relationship between the number of hours per day of intervention and quantifiable outcomes (Bassett, Green & Kazanjian 2000) and recommendations about the most effective levels of intervention vary. The US National Research Council has recommended a minimum of 25 hours per week. However, the amount of instruction and focus of instruction will vary with the child's age and competencies, and the child's cognitive ability and the severity of the autism strongly predicts the effectiveness of interventions (eds Lord & McGee 2001, pp. 57–59).

It is known that multiple sessions of one-on-one intervention combined with small group teaching is effective in many cases, although the optimum level of intensity is uncertain. This must include a high level of engagement with the child, a predictable environment and the involvement of the family to reinforce skills at home (Dunlap 1999). Most researchers agree that intensive behaviour therapy can improve IQ and reduce symptom severity (Charman & Clare 2004). However, many families use multiple therapies (Doughty 2004; Dunlap 1999), rather than one single intervention type.

### **Multiple treatment regimes and models**

The experience of diagnosis can be a traumatic one, and many people react with anger, fear and grief, even though at the same time the diagnosis itself can be a relief when families have their perceptions confirmed by the professionals. Diagnosis also obliges parents to come to terms with the sheer number of services that are thought to be effective for some children with ASD, and the difficulties of gaining access to many of them. This information can be overwhelming and may result in parents refusing to engage in any therapies or, conversely,

using multiple interventions obsessively (cited in McConkey, Kelly & Cassidy 2007). Research into service use by parents has shown that using multiple therapies typifies the experience of many families.

A survey of parents (n=290) participating in the US Multisite Young Autism Project, which used one form of ABA treatment, found that on average children had received seven interventions in addition to ABA (Smith & Antolovich 2000). Similarly, an international online survey of parents of children with autism or Asperger's Disorder (n=479, 78 per cent from the US) (Goin-Kochel, Myers & Mackintosh 2007) found that families used at least six different treatments per year. On average, each child in the surveyed families was currently receiving between four and six different treatments and had tried up to eight in the previous six months. ABA was the most frequently used therapy although most families used medications as well, ranging from vitamins to prescription drugs. A large proportion of families were also using complementary medicines as well as eliminating certain foods from the child's diet. Diet and behavioural/educational therapies were the most common treatments for young children, and older children and adolescents were more likely to be treated with drugs than younger children (Goin-Kochel, Myers & Mackintosh 2007). These findings are similar to those of Bromley et al. (2004), who found that children's involvement in ASD-specific therapies often fell away as they matured, probably because they became more involved in school-based activities and fewer ASD services were available. Most research and service provision in ASD is focused on young children.

Another international Internet survey of families (n=552, 80 per cent from the US) (Green et al. 2006) found that the most common form of treatment was speech therapy. Respondents to this survey were using seven different therapies on average: 52 per cent were using some form of drug therapy, 43 per cent were using vitamin supplements, and 27 per cent were using special diets.

### **Parent perceptions of treatment**

A small number of studies from the UK, Northern Ireland and the US focus specifically on the perceptions of parents of treatment efficacy.

Evaluations of specific treatments have shown high parental satisfaction with speech therapy (Smith & Antolovich 2000), parent-training (Hume, Bellini & Pratt 2005), and an intensive form of ABA known as early intensive behavioural intervention (EIBI) (Webster et al. 2004). Evaluations of the Keyhole and the Frameworks for Communication projects similarly showed improvements both in the children and in the wellbeing of parents (Chandler et al. 2002; McConkey et al. 2003).

Hume, Bellini and Pratt (2005) surveyed parents in the US state of Indiana about service use and perceived efficacy. Speech therapy, occupational therapy (OT), classroom aides and AAC were the most frequently used service types. Parent-training had the highest satisfaction rating, and parents reported it had led to happier interactions with the child and less stress. Sensory integration was also well supported by parents, although there is limited scientific evidence of its efficacy. Most respondents also felt that segregated classroom time had beneficial effects, although once again there is limited research evidence that it is an effective strategy.

Smith and Antolovich (2000) found that most parents were using a range of interventions in addition to ABA, but reported little benefit from them. Although they rated interventions favourably more often than they did unfavourably, they generally described the benefits as modest. (Parental perceptions of the efficacy of ABA itself were not investigated in this study.)

In Northern Ireland (McConkey, Kelly & Cassidy 2007), speech and language therapy was the most commonly used treatment, followed by home visits from health visitors, GPs and educational psychologists. On average, parents had had contact with between five and six different professionals in the previous year. In general, these services were felt to be helpful, but there were five characteristics of professionals that parents identified as unhelpful: failure to follow-up; failure to provide sufficient explanations; pessimistic attitudes towards the child; lack of knowledge about ASD; and insufficient contact with families. Similar findings were reported in a 1999 study of service use of children with ASD in Pennsylvania, in which families' greatest concerns were inefficiencies in service provision and poor communication between professionals (cited in Hume, Bellini & Pratt 2005, p. 197).



Webster et al. (2004) conducted interviews with 15 parents in Bristol in the UK as part of the South West Autism Programme. The children of nine of the parents were receiving a Local Education Authority pilot intervention program for ASD, and weekly contact hours and program goals were negotiated between family and tutors. The other six parents were managing their own interventions based on ABA. Both groups of parents had similar complaints about the length of time they had to wait for diagnosis and about the lack of information about practical help following diagnosis. Both groups also reported that their major concern prior to receiving intervention was how to manage their child's behaviour, especially in public places, and that assistance with specific aspects of behaviour was what they most valued from treatment. All the parents found that participation in the treatment was stressful, but the parents managing their own ABA interventions were particularly stressed by the need to commit a great deal of time and their own resources to the treatment, including coordinating the tutors' rosters.

### **The role of the family in therapies**

As already noted, intensive therapies are expensive. Interventions that rely on parents tend to be less expensive, at least for funding authorities, and are therefore attractive to policy makers accountable to governments (Birkin et al. 2004). However, to date, family-based intensive programs have not shown the same level of successful outcomes as clinically-based ones (Doughty 2004). Centre-based programs have been found to outperform parental-based interventions on intelligence, visual-spatial skills and language (although not on behaviour intervention or adaptive functioning) (Finch & Raffaele 2003).

Some studies have shown the influence of a child's peers, together with naturalistic behaviour techniques, has positive results (Mandell, Stahmer & Brodtkin 2007). Up to 50 per cent of children who participate in these interventions attend mainstream schools. Other behaviour therapies targeting specific behaviours are also reporting promising results, for example, PECS (Picture Exchange Communication System) increases communication initiation in many children (Bondy & Frost 2001).

Nonetheless, while the evidence of any powerful gains in the long term is equivocal, parent-focused therapies do show a number of short-term gains. A small pilot of parent intensive behaviour training showed small improvements in communication skills. The inability of research to cite one type of intervention as preferable over another is problematic for all parents facing choices of early intervention, but there is broad agreement that parent-training and the involvement of parents in treatment plans is good practice (Stahmer & Gist 2001). But if parents are to carry out these roles families need practical support. Hence a first step in any intervention should involve assessment of the family's functioning, at the very least of the parents' level of understanding of their child's condition, if the counselling and education offered is to be appropriate (McConkey, Kelly & Cassidy 2007, p. 17).

It is also important to consider the ways in which treatments can be slotted into family life, especially as some therapies require a great deal of family input. Moes and Frea (2002) found that the most effective therapies were those that took account of the family ecology and revolved around the family's already established daily routines, and encompassed the family's beliefs, values and goals. This is important not only for the parents, but also for the siblings of the child with ASD. They are usually strongly affected by the experience of ASD in the family, and their own needs and desires are too seldom taken into consideration.

There have been a number of studies of behavioural programs that are more naturalistic than ABA. One example involves 'pivotal response' interventions that are not meant to target individual behaviours one at a time, but rather to elicit behaviours that have widespread effects on development, such as being responsive to multiple cues, being motivated to respond appropriately to stimuli and self-regulation (Koegel et al. 1999). Another example is the US Walden Toddler Program, which uses incidental teaching both in the home after parents have been trained in ways to implement teaching procedures in the course of regular living activities, and in the early childhood centre the child attends with children who are developmentally typical (McGee, Morrier & Daly 1999). A further example involves 'embedded learning opportunities' whereby instruction for children with disability is embedded within existing classroom activities and routines (Horn & Lieber 2000). These types of programs can be easily adapted for parents to use (Baker-Ericzen, Stahmer & Burns 2007). Randomised studies have found

that approximately half the children experienced good outcomes from these types interventions (Schreibman & Koegel 2005).

Other examples of frameworks for educating and supporting parents, using a range of treatment models, include the following programs:

- The EarlyBird program: this program incorporates aspects of a range of other programs including TEACCH, the Hanen approach to speech and language development, and the Picture Exchange Communication System (PECS) (see Appendix A), and involves parents sharing videotapes of the child's progress. It is delivered to parents over eight three-hour sessions (Birkin et al. 2004; McConkey, Kelly & Cassidy 2007).
- The Keyhole program: developed in Northern Ireland, this program includes both a home-based intervention and parent-training package, and training and resources for staff at preschools and playgroups. A pre-post evaluation found gains in the child's communication, play and social interactions, and some improvement in the mother's wellbeing (McConkey, Kelly & Cassidy 2007; McConkey et al. 2003).
- The Frameworks for Communication program: this intervention consists of home visits, modelling, workshops and written information, with parents acting as the therapists in naturally occurring situations. An evaluation showed that, after 18 months, the children had made substantial progress in social interaction and expressive communication, including gestural and verbal communication (Chandler et al. 2002).

Educating parents in early behavioural intervention has been shown to have long-term benefits for the child with ASD (Mandell, Stahmer & Brodtkin 2007), and parents find naturalistic strategies like these easier to use than the more structured ones. Parents have also reported that such strategies require fewer hours and hence give them increased leisure time. More importantly, parents using naturalistic strategies reported higher levels of satisfaction with their children (Schreibman & Koegel 1996). Family-centred practice has become widely accepted. It is based on the belief that young children are best served in the context of their whole family. This means that families need to be empowered to work in partnership with professionals, and that their capacities need to be enhanced in order to better meet the needs of the child (Wang et al. 2006). Naturalistic strategies supply the potential for that enhancement while remaining at least partly embedded in what families already know.

## 2.5 Support for parents and families

Despite the fact that having a disability in the family is extremely stressful, many families report high satisfaction with their lives (Trute & Hauch 1988). The *Australian Social Trends* survey (Australian Bureau of Statistics 2005) found that, while caring for a family member can place strain on social relationships, carers commonly reported that relationships with family members were not adversely affected by the need to cope with disability. Some carers said that the disability had brought family members closer than they would otherwise have been. However, even the most capable and optimistic of families need support because the lack of support for people with disability places strains on family life and brings demands that can at times feel overwhelming.

### Types of support needed

MacDermott's study in Western Australia (2008) of 92 families of school-age children with ASD and other forms of developmental disability stressed that it was not possible to plan effectively to meet the needs of the child with ASD without also taking into account the needs of their whole family. The main finding of the study, therefore, was that what families/carers needed above all was access to information and services that would support the functioning of the whole family unit. Examples given included parent-mentoring networks that made use of the skills and knowledge of experienced ASD parents/carers; ASD-specific parenting programs; ASD-specific print, audio and audio-visual resources (especially for families having difficulties accessing intervention services); access to counselling services for all family members; access to ASD-friendly respite services; and a range of sibling support services.

Yet support for families caring for children with ASD is frequently inadequate and sometimes non-existent. Gray's longitudinal Queensland study (2002), for example, found that for some families not only had their situation not improved, it had actually worsened. Although the situation had improved over the ten years of the study for two-thirds of the families, this was not the case for families where the children were violent or became violent at puberty, or for those families whose children had left school and now had nowhere else to go during the day. The lack of services was the chief reason why families believed their situation was worse, particularly the policy emphasis on deinstitutionalisation and the consequent scarcity of residential care. Years of living with daily violence had diminished some people's quality of life considerably. One father reported:

It's just horrifying. It's like a very nasty accident, an assault. If someone assaults you, it traumatizes you. If someone assaults you every day, I'm not sure what it does to you. But we get attacked, one way or another, every day.  
(Gray 2002, p. 220)

The scarcity of services was also problematic for the families whose children had grown to adulthood and no longer attended school, and for those who were worried about what would become of their children when they themselves became too frail to care for them, or died (Gray 2002; see also (1994, 1997, 2002; Gray & Holden 1992).

The provision of adequate and appropriate support leads to reduced stress for families, and lower stress for parents means less likelihood that they will need to seek an out-of-home placement for the child. Moreover, parents who did receive social support engaged in more positive interaction with the child, which resulted in improved outcomes for the child (Rail & Rimmerman 1993). Boyd (2002) also found that informal support appeared to be more effective in reducing stress than formal support (although whether that was because of its limited availability, or because of some factor or factors inherent in formal care, was not discussed). Parental support groups were also found to be a major method of reducing stress.

### **Sources of support**

The stress of caring for children with autism (and disability more generally) falls chiefly on mothers (Boyd 2002), and they report more depression symptoms than fathers (Altiere & von Kluge 2009). At the same time, mothers were more likely than fathers to report that the family sought social support from family and friends, and that they did in fact receive that support (Altiere & von Kluge 2009). The more stressed and/or depressed mothers are, the more likely they are to seek social support. The most effective forms of intervention for mothers are those that both address the child's difficulties (for example, behaviour management, improving cognitive development), and alleviate the mother's stress by providing her with access to social support and training programs. The chief form of support for mothers comes from their husbands, but this is not available to all mothers. Spouses are not always present (Boyd 2002). Moreover, fathers deal with a child's disability in different ways, and these are not always helpful to other family members (Houser & Seligman 1991). A mother is unlikely to find much support from a father whose coping mechanisms include behaviours such as distancing and escape-avoidance. In such cases, service providers concerned with family functioning would need to teach fathers different coping strategies as part of what they expect families to achieve (Houser & Seligman 1991).

Paid employment outside the home can be a significant positive support for the primary carer of a child with ASD (usually the mother) (Dowling & Dolan 2001). Paid employment can go some way towards alleviating the financial stress of having a child with disability, and it also allows mothers to have a role and identity other than being a carer.

There is little research on the importance of social support for fathers. As noted above, mothers report more social support than fathers probably because, as principal carers, they have more need for it (Altiere & von Kluge 2009). Another study found that while social support in the form of friends and family networks can go some way towards alleviating maternal stress, it had little impact on the stress experienced by fathers (Krauss 1993).

A survey of 72 families caring for 75 children with ASD in Manchester in the UK (Bromley et al. 2002) found that families accessed support from a range of sources, as shown in Table 1. The most helpful sources were immediate family, followed by schools and professional organisations.

**Table 1: Sources and helpfulness of social support reported by families with a child with ASD in the UK**

Source	Not available (%)	Not helpful at all (%)	Sometimes helpful (%)	Generally very helpful (%)	Very helpful (%)	Extremely helpful (%)
Parents	35	11	19	7	11	17
Partner's parents	50	17	14	6	6	8
Relatives	40	18	18	10	7	7
Partner's relatives	46	26	11	11	3	3
Partner	14	4	13	22	11	36
Friends	19	18	31	19	13	0
Partner's friends	46	29	13	8	4	0
Own children	22	10	19	13	14	22
Other parents with autistic children	53	10	10	8	11	8
Co-workers	70	8	10	4	7	1
Parents groups	85	1	4	1	3	6
Social groups/clubs	99	0	1	0	0	0
Religious organisations	78	11	6	3	3	0
GP	7	22	32	18	15	6
Early childhood intervention program	85	0	6	4	1	4
School	6	11	11	25	28	19
Professional support	29	4	28	13	17	10
Statutory services	21	19	43	7	8	1

Note: Due to rounding, percentages may not add to 100 per cent.

Source: Bromley et al. 2002.

A later study (Bromley et al. 2004) found that the gender of the child was not associated with any differences in sources of support, with the single exception of higher levels of informal support in families with girls with ASD. Ethnicity, household income and severity of child's behaviour problems were also not found to be associated with any differences in sources of support. There was greater unmet need for support, however, when the child had behavioural problems, when participants felt their house was unsuitable (for example, there were no downstairs toilets), and when the child had language problems. Seventeen per cent of families had used short or long-term respite care in the previous six months.

Gray's 1994 study also investigated sources of support (Table 2). The two most common sources of support were services and family members. The most common reason cited for using services was access to respite, whether for several hours (during school or treatment) or overnight. Moreover, the skills the children learnt at the centre made the lives of the other family members more bearable, and being able to use the centre meant the families had somewhere to turn to in times of crisis. Parents who utilised a service provider seemed to be able to cope better with their children's disabilities than parents who did not. The author noted that most families used a variety of resources, and that no one strategy seemed inherently more successful than any other (Gray 1994).

**Table 2: Primary sources of support reported by families with a child with ASD in Queensland**

Type of support	N	% <sup>(a)</sup>
Use of treatment service (including respite care, special schools and therapies)	14	27
Support from other family members	14	27
Religion	5	10
Social withdrawal	7	14
Individualism (including employment, political activism and recreation)	6	12
Other	5	10

(a) Percentages total more than 100 as families could use more than one type of support.

Source: Gray 1994.

There is an emergent 'formalisation' of social support. One example is the Parent to Parent program, which originated in the US and has since become popular in the UK (Ainbinder et al. 1998). Parents are matched in pairs, one of whom is a veteran supporting parent who has been trained in support techniques and who offers information and emotional support to the other parent. The program is grassroots and the contact is managed by the parents themselves. Parent to Parent was established as a consortium of parent-researchers in five states in the US and received funding from the US Department of Education. Evaluation of the program showed that it was most successful when the parents in the pair had children with similar disabilities, and when they had comparable situations for learning the relevant skills, and comparable availability of support, and when the support was mutual. It did not work when no reliable alliance could be created because of logistical barriers to parent contact (for example, busy lives, long distances, lost phone numbers), or situational and/or personality differences. The researchers commented that, because coming to terms with disability involves talking, sharing, comparing, and learning with others in a similar situation, Parent to Parent programs offer a unique form of support that can effectively complement professional services (Ainbinder et al. 1998).

## 2.6 Families in rural and remote areas

Symon (2001, p. 162) has suggested that one way of addressing the proliferating need for services that has followed on the increase in numbers diagnosed is to expand the provision of health care at a distance, 'via computers, faxes, interactive media, and other technological avenues'. This would also be a way of providing services for children and families in rural and remote areas. As well as technological methods, Symon suggests satellite clinics (which are not staffed full time but where staff come to work at regular intervals), and recruiting local community resources (for example, police, fire departments, churches, other family members) to deliver treatment. In one example, education was provided for parents of children with oppositional behaviour through weekly telephone contact and printed materials. The mothers who received these interventions were more likely than a control group to report reductions in the number and intensity of problem behaviours, improved parenting, increased competence, and decreased stress, depression and anxiety. Another study involved a parent-education program through television. Once again, the intervention group showed more improvement than a control group (Symon 2001). It appears that technology-based training of community-based professional staff supporting families with a child with ASD can be as effective as live training using the Early Start Denver Model, which combines ABA with developmental and relationship therapy (Vismara et al. 2009). However, remote and mediated support is unlikely to provide an adequate substitute for in-person, face-to-face interactions.

Another study investigating the possibilities for families living a long way from specialised services also found that there were interventions that could assist these families. In this case the intervention was an intensive, week-long, centre-based parent-education program using Pivotal Response Training (PRT) that taught procedures for improving social communication for children with autism. It found that there were improvements in the parents' competence in using the procedures and in the children's expressive language use, and that the

parents felt happier, less stressed and more interested in interacting with their children. These improvements happened during the week-long program, but they also lasted for up to a year after the program had finished (Koegel, Symon & Koegel 2002).

These examples of attempts to reach families who are geographically isolated from centres of service provision rely on parents for the provision of treatment. Parents have been shown to be effective therapists if they receive appropriate training. Parental models of therapy are based around reducing problem behaviours, improving the child's verbal skills and increasing appropriate play skills. The inclusion of a support group within the parent education program has been found to increase parent mastery of the teaching techniques they are applying to their children (Stahmer & Gist 2001). Using parents as therapists has the advantage that acquired behaviour skills are reinforced in daily life and hence there is less chance of regression (Schreibman & Koegel 1996). For language acquisition in particular, teaching in natural settings such as home, parks and school leads to faster acquisition of skills than the more clinical approach, because parents are able to generalise the skills (Koegel et al. 1999). Using PRT the family focuses on making widespread improvements rather than concentrating on a more narrow focus (Koegel et al. 1999). However, this does not obviate the need for ongoing support, and this is less available for families in rural and remote areas than it is for those in densely populated urban areas.

## 2.7 Conclusion

The impact of ASD on families is enormous, and there is consensus in both advocate-driven and academic research that families require holistic, comprehensive support at diagnosis. Disability and ASD research in Australia and internationally suggests that such support is not available to many families, who instead experience the process of diagnosis and the post-diagnosis period as fractured and isolating.

There is a growing body of literature on the experience of diagnosis and treatment for families with a child with ASD. Much of this research emerges from the US and the UK, and relatively little is known about the experience of Australian families, and whether or not their experiences are similar to those found in international research. Equally, there is very little available research on families who do not use any support services and how they fare.

Therapies to treat ASD are numerous, diverse in orientation and treatment, and in some cases controversial. Research into parental perceptions of treatment suggests that parents value both evidence-based treatments (such as ABA) and those without robust empirical support (such as sensory integration and vitamin megadoses). Treatments can be delivered as standalone programs, or can be incorporated into eclectic parent training and support packages that also include training of EEC staff and schools. Treatment programs for ASD that involve parents and focus on the ecology of the family, rather than treat children and families as isolated individuals, show the most promise for children and parents. The resources required of parents in acting as therapists are considerable. Social support for parents is therefore critical to ensure that they can continue to work with their children and to ensure their own wellbeing. Innovative program models and methods of delivery also show promise in some cases, and may be helpful in relieving the tension between resources needed for effective treatment and the resources available. This is a significant tension in disability and health services broadly, but it is particularly acute in ASD.

Nonetheless, the resources required by parents to participate actively in these treatments are considerable, and treatment can place further stress on already stressed families. Support from other family members and other families affected by ASD appear to be typical strategies used by parents in Australia and internationally, and also appear to be highly valued.

### 3 Helping children with autism

This section describes the suite of support and information services delivered by the Australian Government from July 2008 called the Helping Children with Autism package. The Australian Government has committed \$190 million for the four years up to June 2012 to deliver the package. Information in this section is provided by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA 2009b). The Helping Children with Autism package includes:

- Autism Advisors, who provide information regarding eligibility, available funding and early intervention and other support services (32 nationally)
- funding for early intervention services
- all eligible children up to their sixth birthday will now have access to the early intervention funding of up to \$12,000 (up to \$6,000 per financial year) for two years
- PlayConnect Playgroups (also available to children with ASD-like symptoms)
- Early Days family workshops
- an ASD website: <[http://raisingchildren.net.au/children\\_with\\_autism/children\\_with\\_autism\\_landing.html](http://raisingchildren.net.au/children_with_autism/children_with_autism_landing.html)>.

The Department of Education, Employment and Workplace Relations (DEEWR) is delivering two initiatives:

- professional development for teachers and other school staff to support school students with ASDs to achieve better educational outcomes
- funding for parents and carers of school students with ASDs to attend workshops and information sessions and to access online workshops and information.

DoHA is administering new initiatives:

- Two new items will be available on the Medicare Benefits Schedule (MBS) for children with autism or any other pervasive developmental disorders aged under 13 years (for diagnosis and treatment planning) and under 15 years (for treatment).
- Psychologists, speech pathologists and occupational therapists will collaborate with the psychiatrist or paediatrician on assessment where required (up to four services per child).
- Psychologists, speech pathologists and occupational therapists will provide early intervention treatment following diagnosis for the child's particular condition and consistent with the treatment and management plan prepared by the referring practitioner (20 services in total per child).

In addition to Helping Children with Autism, six Early Learning and Care Centres, funded through the 2008–09 federal budget, will provide dedicated early learning and care programs for children with ASD (FaHCSIA 2009a).

Data was collected for this project around the time these initiatives were being introduced, and this project is in no sense an evaluation of their impact or efficacy. Many of the changes to service delivery and policies that were recommended by our participants relate to information and access to allied health and ASD-specific services, and Helping Children with Autism is designed to assist families in each of these areas.





## 4 Methodology

As described in the introduction, the purpose of this research was to find out how families provided support for their child post-diagnosis of ASD. Our aim was to interview 30 parents and approximately 10 service providers and clinicians from New South Wales, Victoria and Western Australia. After the commencement of the project, Queensland was also included as it had a service model unique in Australia in terms of service provision.

We interviewed parents post-diagnosis to understand how they made decisions on interventions after receiving the diagnosis of ASD, what they found helpful, how they obtained information, and the support systems they utilised to make decisions. We recruited parents of children with ASD aged less than 6 years old, as this is the time when interventions can have the optimum efficacy in terms of improving speech and social relationships. The research aimed to identify gaps in support and information sources.

Service providers and clinicians were also interviewed to ascertain their views regarding support needs for families, and their views on what families find helpful and unhelpful in the period following diagnosis.

All families and service providers were asked for recommendations regarding improvements to support mechanisms and information sources and delivery. Clinicians and service providers were asked where the main gaps in support and information were for families and recommendations to rectify them.

A qualitative, exploratory approach was most appropriate for the research questions, as this allowed families and service providers to describe their experience of diagnosis and support in detail, and to describe what was helpful in their own terms. Recruitment and sampling techniques were based on our research experience to achieve redundancy and appreciable variations in themes. A total of 49 interviews were conducted between August 2008 and May 2009. The interview schedules for parents and clinicians/service providers are presented at Appendix D. Telephone interviews were conducted with most of the participants. In-person interviews were conducted with six participants in Sydney.

Parents were recruited via letters to Queensland service provider AEIOU, Autism WA, Autism Victoria and Autism Queensland, and through websites and chat rooms (Raising Children Network; Autism Victoria; Nepean, Cumberland, Blacktown & The Hills Service Network Project; Brimbank Autism Angels).

Service providers and clinicians were directly recruited by letter and included speech therapists, psychologists, early intervention service providers, and a generalist EEC centre that enrolls children with ASD. Diagnosing clinicians were recruited from Victoria, New South Wales and Western Australia. Two ASD service providers were also parents of a child with ASD, and in both cases the child had been diagnosed some years prior to interview. They were interviewed primarily in their capacity as service providers but have been categorised separately as they also provided insights on their experience as parents.

The project had ethics approval from the University of New South Wales (UNSW) and state health human research ethics committees (HRECs), and the ethics committees of SDN Children's Services and Autism Spectrum Australia (Aspect, the national ASD peak body).

Interviews were transcribed verbatim and checked against the audio recordings. Identifying information was removed and aliases applied to all interviews. Transcripts were analysed using NVivo qualitative software, using open and axial coding, based on the research questions and emergent themes. Analysis involved the ongoing development and revision of codes to capture the themes as the process of analysing the interviews proceeded. Three researchers coded the interviews, commencing by double coding, and then when coding became consistent between researchers, by single coding and intermittent checking to ensure that coding remained consistent. Quotes illustrative of the themes emerging in these data are presented.

Interview participants are summarised in Table 3. A total of 49 participants were interviewed, of whom 32 were parents. Typically for early intervention disability research, most of the parents (30) were mothers.

We interviewed clinicians in New South Wales, Victoria and Western Australia, and service providers in New South Wales, Victoria and Queensland. A summary of the differences in family experiences between the states is presented at Appendix C.

**Table 3: Participant category, by state**

	NSW	Vic.	Qld	WA	Total
Mother	7	6	10	7	30
Father	1	1	0	0	2
Service provider and parent	2	0	0	0	2
Service provider	7	0	2	2	11
Clinician or therapist	2	1	0	1	4
<b>Total</b>	<b>19</b>	<b>8</b>	<b>12</b>	<b>10</b>	<b>49</b>

Most children who were the subject of the interview (20) were aged 0 to 5 years, as shown in Table 4. Six of the parents we interviewed had two children with ASD; of these, two children were aged older than 6 years.

**Table 4: Age range of children (years)**

Age of child (years)	NSW	Vic.	Qld	WA	Total
0–2	2	1	0	0	3
3–5	2	2	7	6	17
6–7	0	1	2	1	4
8–9	0	1	0	0	1
10–13	1	0	0	0	1
More than one child in family with ASD	3	2	1	0	6
<b>Total</b>	<b>8</b>	<b>7</b>	<b>10</b>	<b>7</b>	<b>32</b>

Table 5 shows the therapies employed at time of interview. Nineteen families were using multiple therapies including speech and OT (the most commonly used therapies), as well as psychology services, chiropractic therapy and diet. Ten families were using eclectic, multidisciplinary approaches at ASD-specific or disability early intervention centres. One family was using ABA exclusively. Two children were not receiving any treatment, and were on waiting lists. Seventeen families were also using nutrition and vitamin supplements (not shown in table).

**Table 5: Therapies currently used**

	NSW	Vic.	Qld	WA	Total
ABA only	0	1	0	0	1
Eclectic	2	1	7	0	10
Multiple	5	4	3	7	19
None	1	1	0	0	2
<b>Total</b>	<b>8</b>	<b>7</b>	<b>10</b>	<b>7</b>	<b>32</b>

## 4.1 Limitations of the study

As noted above, this is a qualitative study and the sample is not statistically representative of the Australian population.

Parents volunteered to participate and were recruited indirectly and via websites and support organisations in accordance with the protocols of ethical research. We therefore spoke to parents who were connected with networks of service and support, and cannot generalise these findings to parents who do not know about or do not use these networks. A number of the parents were extremely active in supporting other parents and advocating for improved service provision, and are probably atypical in their efforts. We asked both parents and service providers about isolated and disconnected parents, in an effort to gather partial data about families who are difficult to reach by usual methods of recruitment.

We interviewed parents in cities and the fringes of large cities, and in regional centres, but none living in very small towns or remote areas. We did not collect demographic information. At least three of the parents interviewed were born overseas and/or had English as a second language, but they were each fluent in English and could not be seen as representative of possible problems due to cultural or language issues.

We did not interview children with ASD or their siblings, and their perspectives are not included here. We recognise that this is a significant limitation of any research on the experience of families with a child with disability.



## 5 Findings

This section reports on the results of interview data analysis, which are organised according to the research questions and themes emerging from the data. The first section describes the period leading up to diagnosis and the experience of diagnosis for families. Section 5.2 summarises the sources and types of information and support for families around the time of diagnosis. Section 5.3 describes the experience of families in assessing, finding and evaluating treatments, and what is helpful and challenging in these circumstances. Section 5.4 describes the role of friends, family and other sources of informal support for families. Section 5.5 summarises the challenges for families whose needs are not well met by existing services and supports. Section 5.6 describes the experience of EEC services, including early intervention services and transitions to school. Section 5.7 reports on the recommendations for change made by parents, service providers and clinicians.

### 5.1 Diagnosis

This section describes the experience of families in the time leading up to diagnosis, the diagnosis itself, and transitions from diagnosis to treatment services.

#### Pre-diagnosis process

Parents are often well aware very early in a child's life that 'there is something wrong'. Typically, the first signals that families notice are the child's lack of social skills or communication skills, or their inability to play. Research with over 700 families (Howlin & Asgharian 1999) found that the parents of children with Asperger's Disorder were usually alerted when the child was around the age of 3 years. But the parents of children with 'classic' ASD often knew their child was in difficulties when the child was around 18 months old, even if they didn't know why. Yet the average age of diagnosis is around 3 years (Mandell, Novak & Zubritsky 2005). While parents can be aware of a problem, they might have to wait anything up to a year to receive a formal diagnosis.

Many of the families interviewed for this study said that they knew early on that there was 'something wrong'. In other cases, it was a child care worker who picked up that there was a possibility of ASD. In Mia's case, her own mother first diagnosed ASD in her daughter, because of her mother's experience as a teacher:

Well, I was in the situation, my mother was a teacher for many years, so she said when [child's name] was 18 months, she said, 'she's not deaf, she's got autism'. We had some very extreme behaviour. (Mia, parent, Qld)

For a number of families, the earliest signs were detected by a day care worker, a preschool teacher or another person closely involved in the care of children, rather than by the parents themselves. None of the children in the families interviewed were first suspected to have ASD by maternal and early childhood nurses or GPs. Pia's son was identified by a teacher:

The teacher was a bit concerned of his behaviour and things that not appear to be his ... you know, what his peers are doing. So they called me up and I didn't sort of believe that at first but they suggested I should, you know, seek doctor's opinion. (Pia, parent, Qld)

On the evidence from the family interviews, it would seem that community nurses and GPs have trouble identifying problems in the development of a child. There appears to be some reluctance to listen to the parent's concerns. For example, Sarah was an early childhood teacher, but even her concerns were dismissed as those of an overanxious mother.

Well, we had a lot of difficulty. I started saying things to community nurses from very early on and was kind of told 'first time mother', also being an early childhood teacher I was overanxious and these sorts of things. We saw several GPs, we saw two paediatricians, and finally had a friend who told me that she had a really great GP and a really great paediatrician and to try them. By that time [child's name] was 18 months. (Sarah, parent, NSW)

Apparently that [not speaking at age 3] was an early warning sign but, you know, the clinic never said anything about it and stuff. We'd had his hearing checked and everything was fine in that department, and you know, we just thought, you know, it was ... he was too lazy to talk sometimes and just, you know, got his point across in his own way. (Hayley, parent, NSW)

The typical process of diagnosis for these families included going through a process of eliminating other causes such as deafness. In Bernice's case, the family tried ear grommets first.

It took a very long time. It took me a year because of ... the people go through hearing, so you'd have to wait to get hearing tests, and then get grommets done, and then get more hearing tests, and then finally after twelve months they said 'yes, well it must be autism'. (Bernice, parent, NSW)

A Queensland study (Skellern, McDowell & Schluter 2005) surveyed paediatricians and paediatric psychiatrists on methods of diagnosing ASD. It found that both developmental and general paediatricians felt that they needed additional training in diagnosis, even though they were seeing up to three cases a week of children with autistic symptoms. The reasons for the dearth of training opportunities are complex, but the limited training available probably reflects the wide variety of ways in which ASD presents. Diana, a clinician in New South Wales, commented on the inadequacy of the training on ASD in the education of GPs, paediatricians, speech therapists and other allied health workers:

It has to be built into the actual medical curriculum, not only the GPs, but of occupational therapists and speech pathologists, you know [...] There should be modules within their training that are dedicated to child development and pervasive developmental disorders, rather than just the one-off lecture. (Diana, clinician, NSW)

As a result, parents have to fight the system to get a diagnosis, and getting confirmation of what they already suspect requires a great deal of persistence.

Basically we just kept going through the mill of, you know, going from one place to the next. (Sally, parent, WA)

I just kept taking him to the doctor and then eventually he referred us onto a paediatrician. (Sonia, parent, NSW)

While parents can recognise quite extreme behaviour from a very early age, they are unable to get a confirmed diagnosis immediately. As Sally reported:

Well, we started when he was 14 months old ... he'd head straight for the walls and flick the light switches on and off, and just stand there and flick and flick and flick, and you could call him and he wouldn't respond. (Sally, parent, WA)

In some cases, the child's behaviour was so extreme that the life of the whole family was disrupted. Steve said:

[B]y the time he was twenty months old, one of us had to remain at home with him while the other parent had to drop the other child off at kindergarten or go shopping, because whenever you took him outside, he would throw a massive tantrum, and I mean kicking and screaming. (Steve, parent, Vic.)

Recognition of the importance of early intervention is growing, and new Australian Government funding is designed to assist families in getting access to early intervention services. Parents, too, are becoming more aware of its importance, but getting past that first hurdle of an early confirmed diagnosis is vital. Martha, for example, found that even the paediatrician had failed to diagnose her son correctly, and her experience has left her with little respect for health professionals:

I thought, you're supposed to be a child professional, and you don't know the first thing about recognising the signs of autism. (Martha, parent, Vic.)

She was very aware of the opportunities lost because of the time delay resulting from the paediatrician's ignorance of ASD:

I just saw it as a big waste of time. He made us kill ... we killed 9 months when we could have been doing something. (Martha, parent, Vic.)

The lack of support for families while waiting for a diagnosis is recognised by the clinicians we interviewed.

Definitely, I think the biggest gap is probably pre-diagnosis, when there's that waitlist situation. I don't think families are given very much information about what they can do while they are on the waitlist. (Fred, clinician, WA)

In response to the recognised need for families before and during the period of diagnosis, service providers and health services have in some cases implemented waitlist options, which we describe in Section 5.3.

### **Waiting for a diagnosis**

Parents reported that public hospitals in all states had long waiting lists for diagnosis. Accessing private psychologists or speech therapists was easier, although that could sometimes be difficult too. We did not systematically collect information on the length of time between first assessment and definitive diagnosis, but a Western Australian clinician in the public system reported an average duration of 12 months, with some variations depending on the age of the child. Waiting for a diagnosis often increases the stress of families who are already under great strain.

There is also an urgency to gain a diagnosis so as to start early intervention programs. Many families reported commencing speech therapy and sometimes OT during this time of waiting, but too often this was largely wasted because the therapists were not fully cognisant of the type of impairments that particular child had.

### **The diagnosis process**

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 (Mandell, Novak & Zubritsky 2005). The assessment can use either the American Psychiatric Association Diagnostic Statistical Manual IV (DSM-IV), or the World Health Organization International Classification of Diseases WHO ICD-10 criteria. In Australia the ADOS (Autism Diagnostic Observation Schedule) and the ADI (Autism Diagnostic Interview) are increasingly used as diagnostic tools. The process of diagnosis usually involves identifying one or more abnormalities across three areas of development. To qualify for a diagnosis of ASD, the child:

must meet at least two of the criteria in social reciprocity, one criterion each in communication and [in] restricted and repetitive behaviours and interests, and fulfil a total of six or more criteria across the three areas. (Lord & Risi 1998)

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. Western Australia has a multidisciplinary approach that uses child observation. 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 (MacDermott et al. 2006).

One parent reported that it took their psychologist 20 minutes to make a diagnosis, while another said that the psychologist wanted them to make seven visits. Given that ASD is a complex set of traits, both may have been valid, but clearly parents have little knowledge about what to expect from the diagnostic process.

One service provider in New South Wales expressed concern about the potential for overdiagnosis:

I think in a way autism is becoming the new ADHD. You know, it's a hot topic in child development at the moment and certainly this last year especially there's been a lot more government attention toward it. So I think that means that we're better at being aware of it and picking it up, but we're also in danger of overdiagnosing as well. (Melissa, service provider, NSW)

This view finds some support from Australian and international research indicating a lack of consistency in diagnosis of ASD, and doctors making a diagnosis in order to ensure children gain access to state and federal funding for ASD (Skellern, McDowell & Schluter 2005; Skellern, Schluter & McDowell 2005; Williams et al. 2008). However Diana, a clinician in New South Wales, raised strong objections to the idea that autism was being overdiagnosed, saying that she had not seen any evidence of it.

After diagnosis, there appeared in many cases to be very little ongoing connection between the diagnosing clinician and the family. Clinicians in our interviews said that they are giving families time to assimilate the diagnosis, and to grieve and recover from the shock. They provide minimal information at this point because they believe the family are unable to absorb much at this time. The information given usually relates to the types of therapies the family should be seeking, rather than to specific recommendations.

We're obliged to be careful about giving firm recommendations. We would, instead of recommending a particularly provider, we instead would give recommendations around the type of therapy and services that we believe the child requires. (Fred, clinician, WA)

Other service providers said they gave the families the names and contact details of the relevant peak body and a few therapists. They seemed to feel that they shouldn't overwhelm the family to start with, and that they would be able to absorb more information later. Further, as discussed in Section 5.2, doctors are often reluctant to recommend one treatment approach over another.

Parents, on the other hand, felt abandoned and confused about where to go next. While many acknowledged they felt grief, they also wanted to start 'fixing the problem'. Parents often expected that their diagnosing clinicians would recommend a service and their child would commence therapy immediately. This expectation is almost always disappointed. Katrina, a service provider and a mother of a child with ASD put it best:

What they do with, this is probably no mystery, but paediatricians give you a diagnosis, hand you a tissue, and kiss you off with a list of people that you're supposed to find out who's a good one, you're supposed to Google, you're supposed to meet all of them. You're grieving and you're dying, your whole family is imploding, but you just go and research all of these, there's no discussion of efficacy, no discussion of outcomes. (Katrina, service provider/parent, NSW)

Parents want and need a smooth transition from diagnosis into therapy. They want case management that can review the diagnosis and work with them to agree on a course of action. Instead, families feel they have been left to figure out for themselves what should be the next course of action. As Ann put it:

[What] I'd like to add is that there is a desperate cry out there amongst the autism community, for people, when they are diagnosed that, and I've heard this story time and time again, not just from myself, but that people are just left hanging. They're told that their son or daughter has a lifelong disability, and then they're ushered out the door and they're totally left on their own as to what to do next. (Ann, parent, Qld)

While it is too early to provide any review of the Autism Advisors, there are indications that they are unable to provide case management for families. Autism Advisors were created in October 2008 by the Australian Government to ensure families understand the diagnosis of ASD and provide information about early intervention. Nina, a health care provider in New South Wales, said that the advisors were only there to 'tick the boxes':

[C]ompleting the form, and then probably go through a number of options available to authorise service provider they can get onto. (Nina, service provider, NSW)

No, no I think that so far ... for us ... from our perspective it seems to have been purely an administrative box-ticking role. They have had no assistance at all with case management, and we've had a lot of disappointed parents and professionals. (Diana, clinician, NSW)



## Summary and conclusions

There are often ‘warning signs’ for ASD well before the child is 2 years old, which has been viewed as the earliest age at which a diagnosis can be made. Parents pick up these signs themselves in some cases, or are alerted to them by EEC teachers or other families. None of the parents we interviewed had been alerted by a GP or child and family health nurse.

Families have to deal with long waiting lists to obtain a diagnosis in the public health system. Many parents opt to go privately to get a diagnosis. Once they receive a diagnosis the information they receive from the diagnosing clinician is often overwhelming and not particularly helpful.

While on the waiting list for a diagnosis the information and support for families is limited.

## 5.2 Sources, types and nature of information

As we described in the previous section, the experience of diagnosis is very difficult for most parents, and this is often compounded by the length of time they have to wait to get the diagnosis confirmed. Based on the interviews conducted for this study, it also seems that the diagnosing clinician is often not a good source of information or emotional support and reassurance for parents. Parents and service providers describe the importance, in these circumstances, of finding out all that they can, as soon as they can.

In the period leading up to and just after diagnosis, parents wanted information on:

- ASD, especially treatment, prognosis and what parents can do to help
- names, details, waiting lists and costs for local ASD programs (including ABA, early intervention, prior-to-school and school programs)
- names, details, waiting lists and costs for allied health services, especially speech therapy
- ‘waitlist options’ for therapeutic interventions that can be started while children are on waiting lists for ASD programs
- some parents, but not all, want detailed research evidence on treatment efficacy.

This section of the report describes parents’ experiences of receiving information, how they assessed that information, and what they felt was helpful and what was not. It also describes the ways in which clinicians and service providers inform parents about ASD, and their views on what is most helpful.

### Information at diagnosis

#### ASD

None of the respondents in this study identified a need for more general advice about ASD, as this seems to be readily available from diagnosing doctors or services, as well as on the web. There are also regular information sessions run by hospitals and peak bodies for parents who have recently received a diagnosis. Three parents said they received face-to-face information (from the doctor at the time of diagnosis, from a peak body, and from a parents’ group); and seven diagnosing doctors/service providers said that they provided it.

The sessions run by the hospitals and peak bodies enable parents to make contact with each other, and provide opportunities for sharing information (see Section 5.4). However, the parents did not say very much in the interviews about the content of these sessions, and one parent said she did not find the session she attended very useful.

I have to say that they’re dealing with that at the level that somebody without having completed high school [or had] English as a second language, might be able to understand [...] And for a lot of people that’s obviously really helpful, but for me, a month after my son was diagnosed, they didn’t tell me a thing I didn’t know. Because as soon as my son was diagnosed I just got on the Internet and I Googled and the first night I joined [a parent group] and really sort of got into it. (Alyce, parent, Vic.)

We discuss the needs of parents with language backgrounds other than English and with complex needs in Section 5.5.

When parents received individualised, specific information about their own child's condition, and they received it in person, this was highly valued. One parent proposed that the best way to receive information would be through a multidisciplinary approach, focusing on the particular domains requiring therapy, and hence clarifying the priorities for intervention.

I think possibly it would have to be a collaboration process with the health professionals. Perhaps a social worker, perhaps a paediatrician who's able to, I guess, advise you based on your child's deficits or challenges. (Vicki, parent, WA)

Only a few parents described experiencing this team consultation, although collaborative, multidisciplinary diagnostic **assessment** is practiced in at least some areas (Western Australia and large hospitals elsewhere). Even those parents who do experience this have to wait.

[T]he problem is parents are not given enough information when they are given a diagnosis. When [a community paediatrician] and her team see you, they give you great information. They talk to you plainly so you can understand it, and they have a social worker there that's available there for you to speak to, and they make sure you have access to every service they believe you need. But while you're waiting for that, you have nothing. (Bernice, parent, NSW)

### *Services and treatments available*

It was a fairly common experience for parents around the time of diagnosis to receive lists of names and phone numbers of therapies and service providers—for early intervention services or for specific therapies, or both—and parents had differing views on how useful this was. There were two parents who would have liked a consolidated list of programs and providers on diagnosis, because they had had to find out this information for themselves.

I think what would have been ideal for us is to, okay, after we get a diagnosis, to get, say, a whole heap of pamphlets or something about autism and about all the different approaches in autism. About supports, about therapies, about everything, all rolled into one little bundle would have been just great. (Gina, parent, Vic.)

There were other parents, however, who did not find such a list helpful because it did not describe what was best for their own child.

I was given that list of numbers [...] but you know they're just numbers [...] and you don't want to go ringing around saying, 'My son has got autism. What do you do?' (Shannon, parent, WA)

[Y]ou get your diagnosis, you get bundled out of the office in the early intervention scenario with, 'Well, there are a number of early intervention providers, they're in this directory which is on the Internet. Ring around and see if you can find yourself a place'. (Alyce, parent, Vic.)

### **Other sources of information**

Apart from diagnosing doctors, sources of information used by respondents included other parents (discussed in Section 5.4), services and peak bodies, libraries, newsletters and books. One newsletter, from ASD educator Sue Larkey<sup>1</sup> and one book, the *Australian Autism Handbook* (O'Reilly & Smith 2008) were specifically noted as helpful by parents (two parents mentioned each).

However, the Internet seems to be the primary source of information. It was mentioned by 11 parents and three service providers/clinicians. This is an area where the views of parents and our other interview participants are in broad agreement. For example, Nancy, a service provider, said:

[Families are] given a 15–20 minute appointment, they walk out with this word, 'autism', and then families just go on the Internet. We know 100 per cent that's the place they're getting information. (Nancy, service provider, regional NSW)

Bruce, a parent, confirmed this view of the crucial role of the Internet: ‘we had an inkling of this, it was straight online’. Similarly, Catherine (who is both a service provider and a parent) said, ‘Without the Internet I don’t know how anyone would find information’.

In common with other sources of information, the difficulty parents find with the Internet is not the volume but the quality of information and its relevance to them. Service providers noted the poor quality of a lot of web-based information. However, these limitations can also be found in other sources of information. Parents said that the information provided by hospitals or doctors could be unhelpful.

[At the children’s hospital we received an information] pack, and the intake worker gave us a whole lot of stuff. But it was just like a maze, it was trying to ... and I think it was called something like that actually, working your way through the maze. (Fran, parent, Vic.)

As one parent describes it, retrieving information from the Internet can be an emotionally difficult experience:

You know like sometimes it just gets a bit overwhelming and ... well, just leave it for another day [...] sometimes you’ll get heaps of information but you don’t actually want it, but then later on you’ll ... you’ll want to know every single little thing about autism. (Lee, parent, NSW)

Another parent had a similar reaction to the amount of information in the package she was provided with. Trying to absorb information while coping with grief was an emotionally draining experience.

I think it’s two things, it’s just information overload, not much guidance as in personal stuff, and also trying to work through it with, I suppose, the sadness, and really it was more about us coping as well. So it’s a double whammy. (Fran, parent, Vic.)

Both parents and service providers talked about strategies to assess the quality of the information provided on websites. The websites of peak bodies and service providers often have links to other websites, and one parent used them as a trusted source to get information about individual service providers and schools, as well as for general information about ASD. Service providers acknowledged that they had a role in helping parents to make informed judgements about websites, but this task was made difficult by the fact that they were reluctant to endorse specific organisations or approaches.

The web was also a resource for some parents to connect with other parents, for example, one parent started a Facebook group. A few parents have used the Internet (and other resources) in taking on a leadership or advocacy role in their efforts to improve the quality of the information provided to parents.

I actually helped with [state health department]. They had nothing and they were starting a parent handbook, so I wrote a big factsheet for them because they have no idea. But you know it’s the parents, they’re the ones the information needs to come from. (Tina, parent, Qld)

Some service providers reported that, rather than simply giving people lists of names and phone numbers, they talked to them about treatment principles and about the importance of individual assessment and treatment plans. Trisha, for example, who works at an early intervention centre for children with a range of disabilities including ASD, felt that staff training was a necessary component of ensuring parents got information about different approaches to treatment:

We keep ourselves informed, and if families ask about stuff [...] we can give them informed opinion. We also try to keep ourselves up to date so that we can implement stuff within our program. So that although we may not be doing RDI [Relationship Development Intervention], say, we’ve had training in RDI so we know what it’s about and so we can incorporate elements of it within our program. (Trisha, service provider, NSW)

### **Managing information ‘overload’**

A number of service providers and clinicians made a point of saying that they tried to manage the amount of information they gave parents at diagnosis. This strategy has been devised to try and avoid overwhelming parents with information, and seems to be a good idea as a number of parents did talk about being overwhelmed.

The problem is that what actually happens is you're given so much paperwork at the beginning, too much. It is, it's just too much. It's just absolutely overwhelming [...] And it's not like it's presented to you nicely in a file or you can look up an index to find something. It's just ... you go and you get another like six bunches of stapled together papers and ... and you're just coming home and you're just piling papers up on top of each other and going, oh my gosh, which ones do I read? Which ones apply to me? (Vicki, parent, WA)

We seem to have been getting advice from here there and everywhere, have a look at this, have a look at that and have you tried that, and have you tried this? It was just so mind boggling at the time. I was still dealing with the fact that we had this horrible word now labelling our son. (Mia, parent Qld)

Once I started writing things down that helped, because I could then say 'oh look, I've talked to this person' [...] and this is what happened, and it sort of gave me a lot to work on. Because I can't remember, my memory is just so bad, it's sort of overload, that half the time I sort of have to start from the beginning again. (Fran, parent, Vic.)

A member of a multidisciplinary diagnostic team at a New South Wales hospital recently conducted a survey of patients a few years ago in which they found that were 'overwhelmed'.

[So we have] changed our practice a bit. We didn't actually go through everything in details on the day of the assessment. So we will do it by a follow-up home visit or a phone call and basically most of the time it's a phone call because of the caseload we have, we can't actually make home visits for everyone. (Nina, service provider, NSW)

Diagnosing clinicians, early intervention service providers and workers at peak bodies described not giving too much information at once, reiterating the views of parents that personalised information is best.

Good studies tend to demonstrate that sometimes both written information and DVD information lies in the bottom of the takeaway bag, and it's not necessarily reviewed by families [...] Probably the most successful way to impart information is in direct face-to-face counselling and in small group scenarios. (Fred, clinician, WA)

We don't bombard them with too much written information. We've got A4 handouts and really simple information saying what is autism but I think the greater part of that is we actually sit down with the family and we draw it for them. (Nancy, service provider, NSW)

We have handouts on different things and they can add that to their books, to their folder to keep it, but we have that in the form of handouts. Rather than giving them a whole wodge of information initially [...] Experience has shown us that you can give the whole package of information and they'll still come and ask you. (Trisha, service provider, NSW)

There is broad agreement, then, between parents, clinicians and service providers that personal consultations, in which parents can ask questions and have them answered, is the best way of receiving information. Beyond provision of information, this approach is also advocated as the best means of assisting parents to find, evaluate, take-up and maintain treatment. However, it seems to be very rare that case managers or family advocates are available to families in the period after diagnosis.

There also seems to be broad agreement that general information on ASD and its treatment is widely available. Parents are either provided with, or find their own information, either before or soon after diagnosis. However, many parents are not provided with the information that will help them decide which treatments are most appropriate for their child. In addition, parents are acutely aware of the urgency of intervening early, and waitlists and other delays to intervention add to their distress.

Delays between diagnosis and treatment are not particular to ASD, and there is also research evidence that the experience of diagnosis of many conditions is often distressing and inadequately supported. However, the **range** of treatment options for ASD, the **contested and complex** nature of some approaches (particularly ABA: Section 5.3) and the very long **waiting lists** for many services make the impact of these delays particularly pronounced for families affected by ASD.

### **Funding and payments**

Parents of children with ASD may be entitled to a range of payments and benefits to assist in the cost of therapies. These include:

- Carer Allowance (child) (Centrelink)
- Carer Payment (child) (Centrelink)
- Carer Adjustment Payment (Centrelink)
- Enhanced Primary Care program (Medicare), introduced as part of the Helping Children with Autism package
- early intervention assistance (FaHCSIA), introduced as part of the Helping Children with Autism package
- state-based assistance such as the Early Childhood Intervention Services program (Victorian Department of Human Services), the Family Assistance Fund (Department of Ageing, Disability and Home Care, New South Wales) and the Disability Service Commission's funding programs (Western Australia)
- an additional one-off payment of \$2,000 made to families who live in rural and remote areas according to the ARIA index (Accessibility/Remoteness Index of Australia) for additional expenses due to the families' location.

It is important that parents have access to information about payments and how to apply for them. One parent talked about receiving help from a charity, and another parent talked about fund-raising efforts she leads to buy equipment for the school her daughter attends. For the most part, however, parents and service providers discussed state and Australian Government funding as the most important source of support. Our interviews indicate that some parents were given very little information, but most received at least some information that they found to be useful. The service providers and clinicians we interviewed also talked about distributing information and application forms to parents. However, the systems of payment information were described by parents, service providers and clinicians as confusing and difficult to navigate. Parents often have insufficient information, and find it difficult to know where to go to get better information. For their part, service providers and clinicians are also confused about the different payments and support packages, and in some cases are reluctant to assist parents in applying for support.

Three parents described actively seeking information from services and clinicians, but even with this active engagement finding it difficult to get what they needed.

I would find that I would ring [the state peak body] and they would say 'well, we don't know' and then I would ring someone else and they would say 'we're not sure'. No-one seemed to know anything. (Ann, parent, Vic.)

Since July 2008 specific ASD diagnosis and treatment items have been listed on the MBS. This means that parents can claim from Medicare a portion of the payment they make to:

- consultant physicians (paediatricians and psychiatrists) to diagnose and develop a treatment plan for children aged under 13 years on referral from a GP
- psychologists, speech pathologists and occupational therapists provide up to four services in total per child per lifetime to collaborate with the psychiatrist or paediatrician on the assessment where required
- psychologists, speech pathologists and occupational therapists to provide early intervention treatment following diagnosis for the child's particular condition and consistent with the treatment and management plan prepared by the referring practitioner. Twenty services in total per lifetime may be provided for a child aged under 15 years (DoHA 2009).

Perhaps unsurprisingly, the inclusion of allied health services as a Medicare item (in the context of a treatment plan) seemed to be poorly understood by both parents and service providers. This could be partly due to timing: we conducted interviews between August 2008 and May 2009, and the MBS items were introduced in July 2008. Sarah not only had to do her own research into the Enhanced Primary Care program, but also had to persuade a GP to complete their part of the reporting requirements necessary for parents to receive the Medicare rebate.

I spoke to a couple of GPs who didn't even know what to do, didn't even know if autism was on the list. So basically I had to go and research all the information and take the forms to them, and I still spent twenty minutes convincing the GP that [...] it was o.k. that he filled out the forms for us. (Sarah, parent, NSW)

Other parents talked about not finding out about assistance they could receive until some considerable time after diagnosis, or only by luck. Hayley, for example, found out about the Carer Allowance (child) while talking to a Centrelink officer about another matter; and Bernice found out about the Department of Ageing, Disability and Home Care (DADHC) family assistance from another parent.

In contrast, seven parents said that they received information from the clinician who diagnosed their child with ASD or from another provider or organisation soon after diagnosis.

The GP that I've got now [is] very good. He said to me the other week when we first started mucking around with [child's name] at speech therapy he said to me, 'do you know about Carer Allowance? [...] You need to go and get the forms and I'll fill them out for you' [...] He was a lot more forthcoming and offered me a lot more in regards to getting help in that way [than previous GP did]. (Hayley, parent, NSW)

[A]s soon as the paediatrician told us about it he also recommended that we went straight to Centrelink and picked up the forms for the Carer Allowance, which we did, brought them back, you sign them and within, I think, a week we received a letter to say that we were eligible, and they even back-dated it a little which was very nice of them. (Bruce, parent, NSW)

Six service providers also talked about providing information on support and payments to parents. This information is sometimes provided through parent support groups or information sessions, or through written materials and information packages. A service provider in Queensland employs one of the parents to ensure that parents get appropriate information.

One of our parents, is actually employed by the organisation and she has, is basically constantly updating, it's basically a resource kit, it's sort of a matrix of all the funding options that exist and how to go about accessing those. So, you know obviously through Centrelink and through Disability Services Queensland and all that sort of stuff. (Sophie, service provider, Qld)

The new funding packages are quite complex. However, other payments, such as the Carer Allowance (child) and the Carer Adjustment Payment are not new, and information on these payments also seemed to be patchy, while eligibility criteria for these payments also seems unclear.

There was also the Carer Adjustment Payment as well from Centrelink, which we were very fortunate to get. But I know the vast majority of people with an autistic child don't normally get that. (Steve, parent, Vic.)

I applied for that Carer Adjustment Payment. We were denied because apparently the event of the diagnosis of our autism wasn't catastrophic enough [...] Apparently it wasn't a catastrophic event because there was a lead up to it, so that was a loophole they dived through to deny us that. I know many families with children with autism who have gotten that Carer Adjustment Payment. (Tina, parent, Qld)

Payments and other forms of financial support are very valuable to parents, who often need to give up paid work and pay significant costs for treatment. None of the interview participants reported being refused the Carer Allowance (child), but as Bernice explains, this payment does not come close to meeting the additional expenses of caring for a child with ASD:

[O]ur Carer Allowance [child] is only a hundred dollars a fortnight so it doesn't cover a hell of a lot, especially if you're paying out twenty-four hundred dollars a year for services when your children are still in nappies and they can't change themselves, and they still need certain types of food and certain types of equipment. (Bernice, parent, NSW)

The new payments were also described as hard to understand and part of systems that are hard for parents and practitioners to navigate. Again, it should be emphasised that our data collection coincided with the introduction of two new significant, complex support packages (Medicare and FaHCSIA) and teething problems are to be expected. However, it also seems likely that the different payments will remain complex. Diana, a clinician, expressed reservations about the capacity of the service system to provide the services to which parents are now entitled:

I explain very carefully to parents that they have the ability to access twenty therapy sessions over the child's entire lifetime as long as the referral is made before the child is fifteen. Before the child is thirteen, up to the age of fifteen. And that it will not cover the entire cost because Medicare will only rebate the proportion that Medicare has

determined is rebatable. And unfortunately there's been a lot of misinformation around and people think they can now get twenty free sessions of therapy for their child. Which they can't, because most private practitioners don't have the capacity to do that. (Diana, clinician, Vic.)

Nina is a service provider at a hospital in New South Wales and she reports that her organisation has devised a 'flowchart' for families to understand the different benefits available, which indicates the complexity of the payment system. This complexity was placing a significant burden on organisations, as reported by Trisha and Katrina:

[O]ur family support worker is tearing her hair out at the moment helping families with the family assistance funding, and helping them, supporting their applications and writing applications with them. (Trisha, service provider, NSW)

[The new packages mean that a parent could elect to say] 'okay, that's my bill for a hundred dollars today. I'll pay 26 and send the rest of the bill to FaHCSIA.' Now if we did that, we'd have to basically hire somebody full time [...] which would mean the fees go up, and we're determined the fees are not going to go up. So we're going to put a series of models to the families of ways they could do it. You could sort of get FaHCSIA to pay everything for you up front, or you can go with a fifty-fifty split. (Katrina, service provider, NSW)

Diana reported that the system is confusing for parents and for clinicians:

[O]ne issue is the issue of how easy families are finding it to navigate between all the different Medicare and Centrelink items. I think it's very cumbersome and I don't think that there's any guidance in the way it's kept a track of for the families [...] During this diagnostic process they might see more than one person and nobody's sure who's charged a 135 or a 110.<sup>2</sup> (Diana, clinician, Vic.)

Criteria for state funding can also be opaque. Even when eligibility is clearly understood by families and clinicians, there may be significant periods of waiting. In New South Wales, according to Bernice:

[E]very parent that has a child with a disability is entitled to two thousand dollars per child through DADHC but most parents don't even know about it. Because they are not given that information. So they find out from other parents and then they have to try and apply and a lot of them are getting knocked back. (Bernice, parent, NSW)

In Western Australia, families need to be registered with the Disability Services Commission (DSC) to be eligible for state funding. Ruby, a service provider, reported that in order to be registered, families need a multidisciplinary assessment.

For state funding they have to be registered with Disability Services Commission. So, the family needs an assessment, a collaborative assessment from a paediatrician, a speech therapist and a psychologist so the processing time to get an initial assessment could take [...] quite a long time. (Ruby, service provider, WA)

It should also be noted that most of the parents who participated in our interviews were engaged with early intervention or other services, and had established relationships with other parents of children with ASD, who were also sources of information. Although several had experienced difficulty in receiving information or support, they had for the most part persisted and were now receiving at least Carer Allowance. However, our interview participants reported knowing other parents who are waiting for diagnosis, or disconnected from these services of support and information, and do not receive anything. Ruby explains the situation of those parents who have not made contact with clinicians or early intervention services:

They wouldn't know what happens after a diagnosis. So, they wouldn't know what services they can access. They wouldn't know about support for their child. A lot of families will go to day care and then their child doesn't manage, so the child just stays at home. [W]hen they get a diagnosis they can access respite, Carer Payment, Carer Allowance. There's so much information that is available once they get a diagnosis. But before that there's nothing. (Ruby, service provider, WA)

### **Recommended changes and promising strategies**

Most parents who receive a diagnosis of ASD want the diagnosing clinician to tell them what services to use, and they want to be able to use them immediately. However, this experience seems to be uncommon. In part this is because services are delivered in different settings and by different providers; in part the costs involved with

some therapies are so high that recommending them is not seen as ethical. More generally, diagnosing doctors are often reluctant to recommend a specific course of treatment for many conditions. As we discuss in Section 5.3, there appears to be a real tension between parents' need to decide on treatment strategies that are right for them and their need to be provided with clear advice. Parents appear in many cases to be obliged to choose when they do not have the resources to make an informed choice.

From our interviews, it seems that the 'worst case scenario' for parents at diagnosis is:

- ▶ the diagnosis is accompanied by an overwhelming amount of information, including the need to act immediately
- ▶ they are presented with an array of possible intervention strategies, with little or no support to assess their appropriateness
- ▶ they cannot secure a place in any of the services they know about and are placed on waiting lists instead.

To ensure that this worst case scenario does not happen, parents, clinicians and service providers provided suggestions and described what has been effective. In (apparently very common) circumstances where treatments with the necessary level of intensity are not immediately available, 'waitlist options' offer families the chance to begin interventions while they are waiting for places to become available (Section 5.3).

A 24-hour helpline was also proposed by one parent and one service provider, as an efficient way of getting personalised information to parents when they need it.

I just honestly think a big thing that could be implemented, apart from websites and everything for the paediatricians to be able to give families more information, there should be twenty-four hour phone line that have either parents who have children with autism or counsellors who have experience with autism that parents can ring up if they've just been told that their child has autism [...] they can ask questions and have them answered instead of waiting for six months to find out simple things like, if you'd been using a visual [aid] for that, your child would have learnt by now. (Bernice, parent, NSW)

In terms of cost effectiveness [...] we could get families to access somebody to talk to immediately after diagnosis and I'd say we'd have to do that through telephone. So having like a 1800 number that families can ring and the people on the other end of the phone are not only talented at giving information but also have a little bit of a counselling understanding, they're dealing with families that are often very isolated. (Nancy, service provider, regional NSW)

Finally, two parents talked about the importance of a sense of optimism. A diagnosis of ASD typically brings intense anxiety about the child's future happiness and prospects, along with grief and the enormous task of finding and using therapies. Families can wait significant periods for diagnosis, for treatment, and then for the treatment to show effective results. Reassurance and positive feedback was mentioned only rarely, but given the intense anxieties parents feel about their children, it seems that encouragement and hope are important. For example, one parent, whose child is enrolled in a couple of early intervention programs, noted the benefit of regular, positive feedback from a doctor she knows:

The one thing I have to say is that every time I go and see my doctor and we go every three months for a review, my doctor says what a good job I am doing. And a lot of times you don't get that from people, so that's really positive support to the main carer. (Jill, parent, NSW)

## 5.3 Treatments and the role of parents

### Costs

The costs of diagnosis and treatment are significant for many parents and recurred in interviews as contributing to the difficulties experienced by families. It should be emphasised that these costs are not unique to children with ASD. Access to affordable, appropriate services and support is a broader issue and affects children with other disabilities and delays: previous research suggests this is especially true of allied health services such as speech therapy (Fisher, Thomson & valentine 2004; Muir, Tudball & Robinson 2008; SFSCNEC 2008).



Notwithstanding this, costs emerged as a significant theme in the interview data, which indicates that it is an important part of families' experiences. ASD also appears to be associated with some specific costs (for example, ABA, described later in this subsection).

The costs discussed most often in interviews were allied health and early intervention services, education and assessment/diagnosis services. The costs of nutrition and supplements were also discussed. A few parents talked about the cost of nappies for older children. Parents, clinicians and service providers also talked about the fact that ASD is expensive to treat and manage, and that some families are consequently vulnerable to exploitation.

### **Allied health and early intervention services**

Speech therapy and OT are typically recommended for children with ASD. There are often long waiting lists for these services, as many children with other disabilities need them. Seven parents talked about paying for these services (as 'stand-alone' services rather than, or in addition to, a multidisciplinary early intervention approach), and that they paid for them because the waiting lists for free services was too long.

The costs of multidisciplinary early intervention services and ABA can also be substantial. This is important because these services were consistently reported by parents to be helpful, and because they incorporate many of the principles that have been established as effective. The costs of ABA vary according to the role taken by parents in acting as therapists themselves, but range from \$10,000 to \$50,000 per year, per child.<sup>3</sup> AEIOU, a centre-based multidisciplinary program in Queensland, costs \$14,000 per child per year. These are intensive programs. Less intensive programs cost less. For example, Lee and Sonia both reported paying about \$600 per year for early intervention programs in Sydney; Bernice reported that the state peak body has group and in-home programs costing \$800 to \$1,000 per year; and Pia said that she had to pay \$150 for a one-day trial program.

### *School*

Three parents talked about the costs of teachers' aides or special needs schools. One parent from Victoria, Alyce, reported funding a teacher's aide herself because of the timing of her son's diagnosis. She was told that applications for aides for the following year have to be made by July, and that because her son was diagnosed after that there was no chance that the school would receive funding. Ann, who was in Victoria but subsequently moved to Queensland, said that she could not choose an autism-specific school as it would have required moving to an expensive neighbourhood:

I would have had to move into this very specific area of Melbourne, which just so happened to be a very expensive area of Melbourne. And I'm a single mum and I would have been having to rent, and I just couldn't have afforded it. (Ann, parent, Qld [previously Vic.]

Bernice, who lives in Sydney, also described the cost of ASD-specific classes, run by the state peak body, as expensive:

[A]nd when your child attends a school that has an [ASD-specific] class, it costs twenty-four hundred dollars a year. So Aspect have good services however I don't believe we should have to pay so much for services that our children frankly need. (Bernice, mother, NSW)

### *Assessment and diagnosis*

Three parents talked about the costs of assessment and diagnosis, although several others noted that they had gone to paediatricians or psychologists 'privately' rather than wait for public health services. We did not probe in interviews for details of cost or ask whether parents had private health insurance, so we do not have systematic data on out-of-pocket expenses. However, it seems reasonable to suppose that families without private health insurance, or those who live a long way from large children's hospitals, would be faced with the choice of waiting for a long time or paying substantial fees for diagnosis, and this assumption is supported by the information we received about waiting lists (Section 5.3) and by what parents did tell us about assessment

and diagnosis expenses. Although the MBS specifies that consultations should last at least 45 minutes, this was not Lee's experience:

He had a very short interview with me, he asked me lots of questions [...] And basically after about five minutes he said, yes he has autism [...] He suggested that I make another appointment and come with my husband and he could discuss it with us and ... and work with us and basically things like that. And now I paid \$300 for that five-minute consultation. (Lee, parent, NSW)

Sarah reported knowing other parents who have paid 'massive amounts' for a diagnosis because they did not want to wait. Hayley has one child with ASD and suspects that her other child also needs a diagnosis. However, she cannot afford to return to her consultant paediatrician at the moment:

[B]ecause at the moment her behaviour is just so over the top that I'm just so drained every day with it and like we haven't got the spare \$1,800 to go and get her assessed. (Hayley, parent, NSW)

Quite worryingly, a couple of the parents in Western Sydney we interviewed had not been told about the Child Development Unit (CDU) clinics at The Children's Hospital at Westmead, which offers diagnosis and treatment plan services, even though information about the CDU, and the clinic referral form, is available online.

### *Nutrition and supplements*

Two parents discussed the costs of dietary supplements. Lee said that she is considering a doctor, who has been recommended by other parents but who is also said to prescribe or recommend a dietary supplement that is very expensive. Maree is paying for vitamins and fish oil, both of which are expensive. Other parents also talked about supplements but in those cases the costs of the supplements were not discussed.

### *'Autism is expensive'*

Parents and service providers talked, beyond the costs of specific treatments, about the resources required to manage ASD. For example, June, a parent from Victoria, said that access to services requires a lot of money and other resources, as well as education:

I think you've got to be very proactive with a lot of resources, education wise and financially to be able to access all the services. I know for example there was a speech therapy group, social skills type thing on school holidays near where we live. It costs an absolute fortune. And even for anyone that's a lot of money to access that sort of stuff [...] So I do think you need to be well off but also have the education to be able to access these sort of resources. (June, parent, Vic.)

Families' capacity to pay may determine the quality and choice of treatments available, although this seems to depend on other factors as well, such as geography. In some areas it was reported that private providers have closed their books and it is easier to get access to public health services than private ones. However, at least one parent, who is using a number of different therapies, said that one of the more valuable pieces of information she got from a paediatrician is that intensive treatment of young children is expensive but could result in considerable benefits.

We will go back to the paediatrician because the other information that the paediatrician gave me—which was really, really useful—autism is expensive. There's no pretty way of saying it. It's an expensive syndrome. I mean it can not be, but [it has to be] to improve it so that [child's name] quality of life as he gets older tends to more towards that normal strain and he does have the ability to get into mainstream school and things like that. (Jill, parent, NSW)

Katrina, an ABA service provider, put it this way: 'We know what parents need, and what we're saying parents need costs a lot of money'. Katrina also reported that parents often take on second jobs. This was supported by Steve, who sold his house and took on a second job to pay for intensive, home-based ABA services. Similarly, Mavis said that she works in the evenings to pay for her child's therapies (not ABA). Katrina also noted that ABA was being carried out by families in more geographically remote areas as the only other option was a more general early intervention that was not intensive enough. Families who live away from metropolitan centres have to pay more for ABA than those who live in the city, because they have to pay for the costs of therapists' travel.

Families who live away from metropolitan centres also have additional costs associated with their own travel to services. Financial support is available for families in rural and remote areas, but not those who live on city fringes.

Children in two of the families were not receiving any treatment at time of interview, and it seemed that cost was not the primary factor in these cases. However, Sonia, a single mother, said that she attended speech therapy only a few times because of the cost, and Pia reported that while her son is receiving treatment now there were times in the past that he was not, because of waiting lists for everything except ABA and the high cost of ABA.

It was not possible for us to investigate this during the research, but it seems possible that clinicians and service providers are more emphatic to parents about the benefits of intensive, early intervention, if they think that the parents have the material and other resources to engage in that kind of approach. This is consistent with what clinicians and service providers did tell us, which is that they try and make sure their advice is appropriate for their parents and that they recommend courses of action that are feasible for the families to undertake. As both June and Jill point out, their decisions around treatment for their children requires substantial amounts of money. These decisions are also based on the fact that they have sufficient educational and social resources to deal with multiple services, manage travel and other arrangements, consult with different clinicians and so on. Families who want these intensive programs, and can undertake them, can choose ABA or other approaches, for example combining speech therapy and OT with an early intervention playgroup. The parents we interviewed who were undertaking these approaches were typically very happy with them. However, they also recognised that it may not be possible for other parents, with fewer resources, to take on the same approach.

Because there is no one right way to treat ASD, and because many of the most effective programs are costly, families may be vulnerable to exploitation. There is some evidence that this has already happened internationally, as chelation therapy, a chemical treatment, has been associated with the death of at least one child. Trisha, a service provider, and Carla, a clinician, both linked the desperation parents feel to try everything possible with vulnerability to exploitation.

[I]f you had a child with any disability you'd want to explore every avenue. I mean I've worked with families where they've had incredibly, incredibly delayed kids that are doing not very much, and spent a fortune on, you know, oxygen chambers, and, I mean I saw this kid once that they used to go to Adelaide every three weeks to have a stomach press to push the blood to her head. I mean it was bizarre, but if you were a parent you'd want to feel that you'd done everything you could. (Trisha, service provider, NSW)

I have some families who [spend] thousands and thousands of dollars on treatments that I know are not going to work. They do keep trying new things and that reflects that particular family's need to find a solution to the problem. (Carla, clinician, Vic.)

New funding and resources for ASD may heighten this risk, as unscrupulous providers attempt to become recognised and recommended to parents. This appears to be happening to some extent, as Sarah, a parent who runs a support group and is very active in advocating for services, reports:

Autism has become a bit of a money making venture to some degree [...] We're finding that we're getting contact from a lot of people who want to push their service or would like us to push their service as an autism-specific service. But yet when we look into these people, they don't really have much of a background to do with children with autism. (Sarah, parent, NSW)

### Waiting lists

Recent Australian research has emphasised the importance of waiting lists, and unmet demand for services, to the experience of human service delivery (Fisher, Thomson & valentine 2004; Rogers & Martin 2002). Our interviews support the findings of this previous research, and indicate that the inaccessibility of services is one of parents' most distressing experiences when their child is diagnosed with ASD. This section describes the reported duration of waiting for assessment and treatment, the impact of waiting on parents and families, and strategies adopted by parents and services for families who are on waiting lists, to ensure they receive at least some support while they wait.

### *Duration*

Most of the interview participants talked about waiting lists. Parents' experiences ranged from a fairly brief wait to as long as two years. Bruce (whose child had been diagnosed quite recently prior to interview), Gina and Fran waited less than two months to get access to treatment. In describing her experience, Fran made the point that she needed to be both flexible and engaged: she said that it was unrealistic to 'just put your name down' and wait for services. Two service providers also said that their organisations made sure that parents can make an appointment within a month of diagnosis. Two parents waited for about three months, including Hayley, who reported that the person who assessed her child went on leave immediately afterwards, with no replacement available to see Hayley's family. Alyce reported waiting four months for OT. Mia waited for six months for a place at AEIOU, a much shorter wait than many others because she was alerted to the service early, via word-of-mouth.

Experiencing, or being told about, long waiting lists seems to be very common. Twelve parents reported waiting longer than six months for assessment services or treatment. In some cases parents waited for months for an assessment for eligibility for a service, and were then put on another waiting list for the service itself. Six parents reported waiting lists for diagnosis as well as for services. Four service providers similarly reported their services (or services they work with) have waiting lists of longer than six months, and in a few cases up to two years. Five parents reported abandoning their place on the waitlist for public health services to pay for private services, in addition to those families using ABA, which is not available through the health system at all. Ann, who 'went private' after being told she would wait for 12 months for an appointment to be assessed, points out that two years is a long time for anyone to wait but is especially critical for young children:

[T]he waiting lists out there are phenomenal. You are waiting for one to two years to get intervention, and by the time that time is up, the child is almost school age, and then it isn't early intervention any more, it's over then.  
(Ann, parent, Qld)

In a few cases the private systems is also stretched, although this was discussed by only three people. Parents Tina (Queensland) and Steve (Victoria) both reported waiting significant periods for private speech therapy, and Tina said that the demand for developmental paediatricians in her area was so great that they had closed their books and it is quicker to go through the public system. Carla, a clinician in Melbourne, also reported that a number of the private therapists she recommends to families have also closed their books because they are 'overwhelmed' with numbers. Carla also expressed disquiet about the new Medicare funding to allow families access to treatment:

[W]hile it's all wonderful to have this new money, the complexity and the amount of administrative [burden] is almost not worth it [...] It's great that there's new money, however I think it's been totally misguided because it's all going into the private sector, it's taking people out of the public sector who we can't afford to lose because we can barely keep our heads above water. (Carla, clinician, Vic.)

### *Impact*

Although waiting lists are commonly reported in research and our findings in a sense reinforce what is already known, the effects of waiting for services will be reported here as these effects are a very strong theme in our interviews. Several parents talked about the frustration and distress of wanting to act and being unable to do anything: for example, Ann, Fran and Gina stated:

[O]n the one hand they say to you 'the earlier the intervention, the more hope your child has of leading a fulfilling life', then on the other hand they're saying 'but you have to wait a year to two years to get any help'. And for me and every other parent out there it is so frustrating and you just feel so helpless as to what to do [...] And just hearing, feeling this time ticking away and nothing being done for my son. And I know that most parents out there are feeling exactly the same when their children get diagnosed, so that's the main thing I wanted to sort of put across. (Ann, parent, Qld)

All parents want is just something to happen with the children. That's all we want. And we sort of, other things are minor, but that wait, and knowing that there's an 18 month wait [...] is just awful. (Fran, parent, Vic.)

But the thought of sort of finding out in June about the diagnosis and then having to wait six months for some intervention is really hard. Because you want to, now you know you want to help the child, you know. (Gina, parent, Vic.)

Service providers also talked about the impact of waiting on families, and the role it plays on parents' decisions around therapies:

We don't keep a waiting list. [...] If a family comes to me and I can't see them, I will send them to another ABA service provider and just say 'don't worry, your kid doesn't have time to wait on our waiting list, really. I'll call you if I get a spot, and I'll keep your name here, and you call me again in a month if you're desperate' [...] The worst thing you could possibly ever say to a family who's child has just been diagnosed is, 'you're on our waiting list'. How can you put a two and a half year old on a waiting list, it's disgusting. (Katrina, service provider/parent, NSW)

[T]hey get the diagnosis of autism [...] and they're given [a contact list of service providers]. Then they do what all parents would do, which is go through the list. They ring [the peak body] and they get told 'well you can put your name on the waiting list', they ring us and get told 'you can put your name on the waiting list' and then whoever offers them the spot first is the one that they'll take, because they want something. (Trisha, service provider, NSW)

### *Management strategies and 'waitlist options'*

Parents and service providers described management strategies around waiting lists. Waiting lists recur as a common, and troubling, concern in research. The enormous demand for allied health services, especially free or low-cost services, is a systemic problem that affects families with ASD but is not particular to those families. Strategies to deliver some form of services to children and parents while they wait to get access to the services they need therefore seem promising, especially if they can be duplicated elsewhere. It is enormously distressing for parents to feel that they are 'doing nothing' while they are waiting for services, and if waiting lists are inevitable then parents are likely to feel lesser distress if some form of therapeutic intervention happens.

Among the service providers and clinicians interviewed, three talked about group programs as waitlist options for children. Western Australia's peak body Autism WA has what is described as 'an introduction to autism-type program' for families of newly diagnosed young children waiting for definitive services. School age children, who have to wait longer for both assessment and services (12 to 18 months compared to 6 months for the younger group), get introduced to services and information, for example, about the Carer's Allowance, prior to the diagnosis being confirmed by a multidisciplinary team. Similarly, there are at least two early intervention playgroups in Sydney and one other in Northern New South Wales for children on waiting lists. These are described by Trisha as available to children on waiting lists for more intensive services:

So there's something for them. I mean our playgroup is actually staffed by an educator, a physio and a speech pathologist, so it's pretty intensive waiting list therapy [...] they don't have all the things like individual family service plans, or really specific individual educational programs [and] because it is a waiting list thing and kids drop in and out. But the staff do plan for the kids from week to week. (Trisha, service provider, NSW)

At the same time, it should be noted that a number of service providers and parents were emphatic that intensive services, of at least 10 to 15 hours per week, are necessary to be effective, and that playgroups of two hours a week are unlikely to make a difference to children's communication skills and behaviour. Two parents were also extremely frustrated by the experience of waiting a long time for services and then finding they were inadequate, or delivered only for a short time. Supported playgroups seem to be a promising practice for families while they are waiting for individualised, and intensive where necessary, services; but only if they are available when families want them, without having to wait. It should also be noted here that parents reported quite different experiences of playgroups and similar programs that run for fewer rather than longer hours. Gina's son was attending an early intervention playgroup before he got diagnosed, as she was concerned that there was 'something different about him'. They still attend that playgroup, which has children with a range of disabilities and staff who are knowledgeable about ASD. Other parents also describe their experience of group-based early intervention as helpful.

In contrast, other children require intensive, one-on-one treatment such as that provided by the ABA model. This was described in stark terms by Tina, who described her experience of a playgroup for children with disabilities:

My son's behaviours were so extreme, he had no compliance [...] and all these lovely little kids with their speech delay or other disabilities would sit in a circle and try and sing. But my child would be screaming, it was just ridiculous.  
(Tina, mother, Qld)

Trixie tried a mainstream, music-based playgroup but decided against it in favour of ABA. Describing her decision as a choice between the playgroup and ABA:

ABA wins hands down now that I know what it is. I've had [people] comment, oh, you need to let him just be a normal boy. Well, him being a normal boy, he's either going to be sitting there stimming [repetitive body movements characteristic of ASD] or he's going to be destructive. (Trixie, parent, Vic.)

Centres and clinicians are also delivering services in innovative ways in response to strong and growing demand. For example, Mia, a parent in Queensland, reported that the state peak body had formed a 'roving team' of staff who would attend generalist EEC services to train the staff there, because the waiting list for their own services was so long. In regional New South Wales, as reported by Nancy, one speech therapist is apparently so oversubscribed that she is advising parents on the basis of observing their interactions via DVD:

[S]he's so full that to try and give families some support she's actually getting the families to film their interaction with the children, send her the DVD, she watches it, gives them recommendations and sends them back to them. Because she doesn't have time to literally see the amount of families that are trying to access her. (Nancy, service provider, NSW)

Innovative use of technologies are unlikely, however, to provide an adequate substitute for the individualised, in-person support that families, clinicians and service providers all identify as helpful for families. In Western Australia, the Western Australia Autism Diagnosis Forum (WAADF) updates its list on a quarterly basis of service providers waiting lists so that diagnosticians can choose service providers with shorter lists to refer families on to. All those interviewed from the state ASD peak bodies said that they were trying to provide information and ideas about what families could do while waiting for a diagnosis, but what they could provide was largely limited to group work for a couple of hours a week. There are pre-diagnosis playgroups in most states. Autism WA has been given funding by FaHCSIA to provide Saturday playgroups for families waiting for early intervention. In Queensland, the Special Education and Development Unit provides playgroups for children with all types of disabilities, and these have proved to be a great source of informal networking for mothers waiting for a diagnosis.

Some parents also found other tactics to be effective, such as ringing the programs they are waiting for and reminding them. Two parents started up in-person or Facebook groups to make contact with other parents. These parents also recognise that this takes considerable resources, and not all parents will have the capacity to do it.

I know how the system works, and I just ring up and I push and I say 'hi, I'm really keen, great, put me on the waiting list'. And then I ring back every eight weeks and say 'so, how am I doing?' I just wonder, I mean for those parents who actually have Asperger's [...] I've met quite a few of them where I just go 'oh lordy I don't know how you're coping'.  
(Alyce, parent, Vic.)

These interim services suggest a model of service delivery, of options that are offered while the family is on a waitlist for intervention. At a minimum, these educate parents on interventions they can implement while waiting for more intensive intervention and provide some advice on circumventing the more extreme behaviours that can be displayed by children with ASD, and so possibly prevent them becoming entrenched.

## Applied behaviour analysis

Applied behaviour analysis (ABA) is a behavioural intervention. Roberts and Prior (2006, p. 37) summarise ABA as:

[A]n intervention in which the principles of learning theory are applied in a systematic and measurable manner to increase, reduce, maintain, and/or generalise target behaviours. The goal of ABA is to improve **socially significant** behaviours to a meaningful degree. These behaviours include reading and other academic skills, social skills, communication, and adaptive living skills. Adaptive living skills include gross and fine motor skills, eating and food preparation, toileting, dressing, personal self-care, domestic skills, time and punctuality, money and value, home and community orientation, and work skills ... assessment of outcomes of the intervention are dependent upon the ongoing objective measurement of changes in observable behaviour (i.e., before and after intervention) which then informs the goal selection and decision making process for ongoing treatment and progress.

Evaluation research has shown that behavioural interventions have produced positive outcomes, but ‘there continues to be a great deal of controversy about particular behavioural interventions and programs and differences in the interpretation of research findings’ (Roberts & Prior 2006, p. 50). Due in part to the intensity of the program, the cost of providing ABA programs is high—up to \$50,000 per child per year—and parents are required to cover 100 per cent of these costs as there is no public funding provided.

In many respects ABA is one treatment option among many, albeit one that is better supported by research evidence than some others. However, our interviews with service providers and parents revealed that ABA warrants specific attention for a few reasons:

- First, it is very expensive and time-intensive, and represents an enormous commitment from parents, who therefore want objective advice on its suitability for them.
- Second, while it is possible to offer behavioural interventions in combination with other approaches in an eclectic treatment program, some early intervention programs will not accept children receiving ABA, and some ABA services will not offer any other programs. That is, while it is theoretically possible to combine ABA with other approaches, in reality many parents have to choose between ABA and another program, and this can add to the difficulties they face in finding, assessing and choosing treatment options.

We describe both of these in detail in the following sections.

### *Choosing ABA*

As noted previously, ABA is supported by robust research, but this evidence and the controversy about ABA’s outcomes is dense, complex and technical. It seems unlikely that the majority of parents are sufficiently literate in clinical evaluation literature to be able to assess this evidence for themselves. Equally, it seems unreasonable to require parents to do so.<sup>4</sup> Accessible, individualised advice as to the likely benefits of ABA for **their** child is needed by parents, a need identified by both parents and service providers.

Diagnosing clinicians and peak bodies are often reluctant to make specific recommendations about treatment programs to families, because of the importance of individual assessments and tailoring a program to meet a child’s needs. It seems that this is heightened in the case of ABA. It is not always clear why parents didn’t receive the information they wanted about ABA, especially recommendations about whether or not to use it themselves. It may have been because of the reluctance of service providers and clinicians to make general recommendations in the absence of a specific assessment of the child’s particular needs, or it may have been because the service providers and clinicians distrust ABA. For example, one parent described actively pursuing information about ABA, first from a local parent-run group that endorses ABA:

I just ran scared because it was just an enormous undertaking [...] it was like fifty grand a year and we just thought oh, that just sounds insane. (Tina, parent, Q1d)

She then asked her paediatrician about ABA, when there were no places available in the program the paediatrician had recommended, but ‘he just sat on the fence and said look, I’m not commenting on that’. Next, she spoke to the state peak body:

[T]he counsellor that I spoke to just said, no [the parent-run group] are run by emotional parents and there's no way that they would endorse an ABA program. So I walked away scratching my head going, well what the hell do I do here? (Tina, parent, Qld)

Tina eventually did choose ABA, but her experience of trying to find a treatment program was of a paediatrician declining to give information on ABA, long waiting lists for other programs, a very daunting prospect of ABA as expensive and intensive, and what she regarded as very unhelpful advice from the peak body. While Tina's experience was fairly extreme in that she went to three separate sources and got conflicting advice from each of them, other parents also talked about wanting more information about ABA than they could get.

ABA service providers also described frustration at the reluctance of diagnosing clinicians and health workers to provide information about ABA to parents. One ABA service provider described presentations to support groups and parent bodies, and having speech pathologists and other workers respond with what she regards as antagonism to ABA:

[S]peech pathologists from other groups [...] will stand up and say 'we were taught that ABA is totally wrong' [...] I don't expect a speech pathologist to do ABA, but I would expect that they would see it as an open option for parents, that they wouldn't actively discourage it, which they do, give out misinformation about it, total misinformation. (Lydia, service provider, NSW)

Three parents reported being told that ABA is expensive when they inquired about it, but one parent said that her son's diagnosing doctor provided additional (and as it turned out inaccurate) advice:

[T]he doctor that diagnosed my son said, we said 'we'd like to try this ABA', and he said, 'well you'll go broke and you'll get divorced'. (Katrina, service provider/parent, NSW)

ABA is often the only option in regional and rural centres. This makes it difficult for parents who do not want to use ABA or who cannot afford it. However, even parents who do want to use ABA may find it difficult to get information and support. Trixie, a parent from regional Victoria, found it difficult to get information on ABA. She was referred to an ABA provider, but the ABA provider also operates as the only ASD resource centre in town:

So I rang them and their rules are they're an autism resource centre, they're not an ABA resource centre. [...] So they're very, very supportive, but the rules of the organisation are that they can't promote it. So they can't promote one therapy over another. (Trixie, parent, Vic.)

### *Using ABA with other approaches*

Our interviews indicate that ABA excites strong opinions in parents who use it, and in both ABA service providers and other service providers. This strong reaction to ABA was also described by Catherine who is both a parent of a child with ASD and a service provider. She described being wary of recommending ABA to others, in part because it is so expensive, but for other reasons too:

Some people just don't like ABA. There's a whole lot of sort of beliefs around, it produces robotic children and you start off initially with a food reward and that puts a lot of people off. (Catherine, service provider/parent, NSW)

Mavis also described ABA as being incompatible with her family's practices and values:

We're not into ABA in this home. No, we believe [...] that a child should grow in the way of play and learn through that way [...] You know yes [ABA] may help him with sitting at a table later on in life, but let him just grow now as a child. (Mavis, parent, WA)

Lydia, an ABA service provider, reported incorporating another approach, relationship development intervention (RDI), for a while but stopping this because of conflict between the messages from RDI and ABA about the sequence of interventions. Non-ABA service providers also described the incompatibility of ABA with their approaches.

If kids go to ABA we don't see them here, because it's a totally conflicting philosophy to what we do, and it just doesn't work in the way that we do. I mean shadows don't work in our setting, and because we support kids into preschool it's not a model we work with. (Trisha, service provider, NSW)



Some parents have found services that use ABA and other approaches. It appears then that parents may be able to use ABA as one of a number of therapies, but this depends, in part, on where they live. However, even those parents who are offered ABA with other services may be confronted with difficult decisions about managing these multiple services. One mother, Martha, described being offered a place in an integrated EEC setting, in which both children with ASD and children without disability are enrolled. However, participation in this program meant fewer hours each week available to participate in ABA, and Martha received advice to decline it on these grounds, a decision she now regrets:

I won't say who, but a professional said to me, 'well it will reduce his ABA hours so don't [take the early education setting place]'. And I thought, and I was really desperate, I just needed somebody to say 'this is what you do'. And so this somebody said 'don't do it because it'll be less ABA', and I thought 'okay, I won't do it then', and I should have. (Martha, mother, Vic.)

Some parents and service providers emphasise that ABA includes teaching parents to modify their behaviour and parenting, and describe the capacity of some parents to adopt a 'DIY' approach. For example, Ann, a mother from Queensland, found that ABA was too expensive for her to do through a centre-based setting. Instead, she completed an ABA course herself, as did her son's early education teacher, and complemented this with six monthly consultations with a psychologist.

I opted to do the therapy myself, learn how to do the therapy [...] I did a course and I had a psychologist who was, once a month I would meet with her and we would update my son's program and see how he had progressed. And [...] my son's kindy teacher at the time, she also got trained in it. We did, we were basically doing a session with him each day, which was two to three hours, about six days a week, and I was doing the majority of that therapy. And I did find it excellent. (Ann, mother, Qld)

Tina also found a home-based ABA program appropriate, as it was in line with her very strong preference to play a central role in her son's daily life when he was very young:

I mean if [centre-based service providers] had said we had a program for your 2 year old, come and send him here five days a week because he needs at least 20 hours a week of intervention, I would have said that he's 2 years. I personally am not into handing my children over, I like to be as much a part of the solution as I possibly can. Particularly at that tender age of 2 years, that's too little, so I'm a really big advocate [for] service providers [...] doing these home programs. (Tina, mother, Qld)

Steve is a father from Victoria who took a very different course of action from Ann. He and his wife did their own research into ABA and directly recruited therapists by advertising at the local university for psychology students to work with their son. (ABA service providers in Australia run their own training programs for junior ABA therapists, and many recruits are psychology students or graduates.) Steve's wife gave up paid work for a year and they sold their house to fund the intensive home-based ABA program they believed their child needed. Nevertheless, while Steve's family had a much more intense level of ABA intervention than Ann's, Steve also emphasises the role that parents and siblings have to play in implementing ABA principles in everyday life:

So there's a lot of training that we had to do in the family. Even his older brother, who is, his older brother is only five, he has required training as well so that his younger brother [with ASD] has to ask him for things. (Steve, father, Vic.)

Another aspect of ABA that service providers and parents discuss as critical is its intensity. Katrina points out that ABA is expensive not 'because you're buying an A grade version of therapy [but] you've got to buy a lot of it'. Diana is a clinician who is reluctant to recommend specific therapeutic approaches but describes the most effective approaches as those that are intensive, at least 15 hours a week, and involve parent training. Tina, a parent who is a strong advocate of ABA, nevertheless says that other interventions may also be effective but they have to be intensive, at least a few hours a day.

This is supported by the research conducted by Roberts and Prior (2006), who argue that effective therapeutic approaches are characterised by the engagement of family members in collaborative partnerships.

## Parents' role in treatment

Parents often take an active role in their children's treatment for ASD, and successful interventions are characterised by the engagement and support of parents 'in a collaborative partnership with professionals involved in the delivery of treatments' (Roberts & Prior 2006, p. 14). This can be very intensive: centre-based ABA programs, for example, can involve the attendance of parents and children for up to 30 hours per week. Even where the role of parents in treatment is not so intensive, parents are still obliged to be active in finding treatments, managing appointments, and in many cases acting as therapists and case managers.

### *Choosing therapies*

One of the most important roles that parents play is in choosing treatments for their children. Eleven interview participants described the array of treatment options possible for ASD as overwhelming for parents, especially around the time of diagnosis. Because there is a wide range of treatment types, waiting lists and costs, parents are often required to make decisions when they do not feel that they have sufficient information to do so. Carla, a clinician from Victoria, said that parents should not be presented with a range of options and be invited to choose one of them:

What I don't believe you should do as a professional, is you shouldn't say 'look these are the options, you make the choice'. Because I think parents come to you as a professional to get your professional guidance as to what you think is best for their child [...] Of course it has to be family-centred practice. But that doesn't mean you say to the parent 'well what would you like me to do for your child? You make the choice'. Because they don't know what the choice is. (Carla, clinician, Vic.)

Nevertheless, that precise situation was reported by several parents, who described it as extremely difficult and distressing. Vicki said that she has spoken to many other parents of children with ASD who were in a similar situation to hers:

And they're quite overwhelmed by it, they're worried they're going to make the wrong choice, they're not sure what all their choices are. (Vicki, parent, WA)

Fran, Pia and Bruce also describe being overwhelmed by the obligation to choose:

We had a lot of people that we spoke with, and it was like 'you're the parents, you make a decision, it's okay', and we just wanted someone to tell us. Sometimes it's just easier to hear it. Because we had to make so many decisions that left didn't know what right was doing. (Fran, parent, Vic.)

People are throwing options at you, but I don't think you can expect anyone to tell you what is best, because everyone's an individual and no-one knows our son like we do, but we're just terrified we're going to make the wrong decision. (Bruce, parent, NSW)

[I]'m still not sure if I'm making the right decision [...] I'm just always afraid, what if I make a wrong, you know, decision. And then everyone [may] come back and say, you see, you should have done this and that. (Pia, parent, Qld)

As Trisha, a service provider describes it, the prevalence of waiting lists and the fact that choosing one service can preclude use of another is especially pressing for families with ASD:

A real dilemma for families [is] making that decision as to whether they want to go to the specialist service for a year, and then come back and maybe, or maybe not, get a place with us. And that's families' choice, but that's a dilemma for them [...] The dilemma for parents with a child with any disability, is choosing the right service, but particularly I think for family of kids with autism because there's such an array of choices with varying degrees of costs. (Trisha, service provider, NSW)

Parents, of course, want to choose the service that suits their child's needs and their own values and practices best, and three parents described being able to do so. Parents Sarah and Maree, for example, talked about being able to choose between services, based on what they thought was best for their child. Vicki, who works with a case manager, talked about valuing the opportunity to discuss the goals and objectives of her child's treatment and change them if needed. However, this genuine choice is very different from the obligation many parents feel to make a decision when they are not equipped to do so.

### *Finding and working with services*

When parents have found and chosen services, they are often involved in their child's therapy. This may involve playing an active role in their child's education. Five parents talked about working with their child's early education care service or school; for example, to advocate for specialist aides or teachers, or to assist teachers in developing learning programs. Two parents talked about passing on information from Sue Larkey's newsletter to teachers' aides.

In other cases, parents attend support groups or play groups with their child: six of our interview participants reported doing this. As we describe in Section 5.4, contact with other parents of children with ASD is often very helpful for parents. Attendance at these groups can also be 'training' sessions for parents, in which they learn new ways of communicating with their child or responding to behaviour that they then continue to use at home.

Parents also undertake serious training and education, at their own expense, as described by Maree and Sarah:

I think it's a lot, it's up to the parents. So we've been working with them, my husband's done the More Than Words program [...] I've done an ABA course. I've been to Autism Queensland and done two courses there and we went to the global, the conference as well. So we have been doing quite a bit of training. (Maree, parent, WA)

I've developed a complete PECS system myself for [child's name], because after doing a bit of research thought that it might be something that would help him. So I made all my own cards and we did, we've now developed that into Social Stories and other areas. It really all still comes down very much to research and making that contact with other people. (Sarah, parent, NSW)

Other parents talked in detail about the efforts they make in terms of coordinating multiple treatments and therapies, consulting with multidisciplinary teams and arguing for different goals and objectives from those preferred by clinicians. A couple of parents referred to themselves as their child's 'case manager' and several others described roles and activities that could well be described as case management. The parents of children who did have case managers found them extremely helpful. Parents who were acting as case managers themselves did so because the services they were receiving were fragmented and delivered in isolation. Mabel, for example, took her child to speech therapy and OT weekly, but neither therapist specialised in ASD and they never communicated with each other:

So they weren't giving me guidelines of: you should be doing this much practice and [...] this much activity and this much massage and you know practicing this [...] It was basically, you did your weekly sessions, you were given a bit of homework to do and that was it. (Mabel, parent, Qld)

In common with several other parents, Mabel did her own research into, as she describes it, 'early intervention and the importance of consistency and frequency [...] getting in and shaping behaviours at such an early age', in order to take on the role of managing her son's treatment in a more holistic way.

Parents of children with ASD may commit significant amounts of time and effort, as well as money, in getting their children to and from appointments and coordinating multiple types of treatment. The children of fourteen of the parents we interviewed were receiving multiple treatments, such as speech, OT and ASD early intervention. The logistics involved in this for some parents are illustrated by Mia's description:

Wednesdays were the shocker days, they were just a nightmare [laughs]. He'd have his SEDU [Special Education Development Unit] from nine to eleven thirty and then I'd pick him up from eleven thirty and drive to his speech therapy appointment at twelve o'clock which would last an hour, from twelve to one. So that was every Wednesday and then every second Wednesday from about quarter past one until quarter past two he had OT. Every fortnight we would have SEDU, then speech, then OT. (Mia, parent, Qld)

Even intensive therapy centres require a large amount of parental involvement.

The parents are part of the program. Every morning, they come in and work with us and the kids and then the parents go and we have what we describe as a bit of a stealth mode approach where the parents have a chance to come in and observe the kids, but the kids can't see them because often they're quite different when parents are around to when the parents are not. So they can actually see what they are doing, so we have a parent roster for families coming in with that. (Sophie, service provider, Qld)

The comments from parents reported in this section are fairly typical of the interviews we conducted. We spoke to only a couple of parents who described being less engaged than this in their child's therapy, or whose children were receiving minimal or less intensive therapy. However, it can be assumed that many parents would not have the resources or time to take on these roles. This assumption is partly confirmed by Kerry:

[M]ost parents make genuine attempts to follow advice, some parents just find they're overwhelmed and just can't do anything and some have done part of the recommendation such as engaging with services, but seem to have a lot of difficulty in actually implementing the details of the therapy that's recommended. So, for example, using visual supports in their daily life and in daily interaction with the child. (Kerry, service provider, NSW)

### *Parents as therapists*

Fifteen interview participants discussed the role parents play in acting as their child's therapist. For three parents, this role includes learning and using sign language, because their child cannot speak. Three other parents and two ABA service providers talked about the role of parents as therapists in ABA programs. As Katrina explains, in the centre-based ABA program she works with:

[Y]ou can either come here and pay fifty or sixty thousand dollars, and have somebody take care of everything. Or you can come here and pay five, ten thousand dollars, and have us supervise a program, and you do a lot of the man hours yourself, we'll train families how to do it. So there's no way that this place is full of rich people who just all have money to throw around, but it's full of incredibly dedicated people who, you know, we have parents here who are their child's therapist around the clock. (Katrina, service provider, NSW)

Steve and his wife ran an ABA program from their home, which involved recruiting therapists themselves and having therapists in their home for many hours a week. In addition to these tasks of recruiting and coordinating ABA therapists, Steve's wife also underwent training in ABA and speech therapy, because they feel very strongly that an important component of therapy is training family members as therapists:

[M]y wife had to give up her job for a year, and had to set up the ABA program, coordinate the speech therapy as well as looking after my other son [...] We've done intensive speech therapy during the ABA therapy, and like I said, it's about training you as a parent. (Steve, parent, Vic.)

Tina also coordinates an ABA program and speech therapy for her child in their home, and also values the training she gets through her involvement in the therapy:

I'm so used to being involved with my child's intervention that, to lose a home program, to lose that support in my home that was there everyday and to lose the speech and OT on top of that we'd just be flailing. We need it at home. It's one thing for him to be at a school and learning beautifully but these kids need to generalise their skills and so he could come home and bring none of the skills with him [...] My speechy trains me a little bit in prompts so it's important he gets that input every day. (Tina, parent, Qld)

Parents using ABA and ABA service providers also described the importance of other family members interacting with the child with ASD in specific, consistent ways.

I didn't hold back in telling [extended family members] how it should be done. And I was really quite, because in the beginning of an ABA program everything has to be quite, everything is quite structured and rigid. And you deliver an instruction in a very specific way and use exactly the same words. So I cut back everyone's vocabulary quite significantly, 'this is how you talk to them'. (Martha, parent, Vic.)

[My son] doesn't get anything unless he asks for it, even if it's one word. So there's a lot of training that we had to do in the family. Even his older brother, who is, his older brother is only five, he has required training as well so that his younger brother has to ask him for things. (Steve, parent, Vic.)

ABA is not the only program to involve siblings and extended family, and other approaches also offer training for parents. For example, Nancy, who works for a state peak body, describes the participants at her organisation's programs as often 'mums but it could be mums, dads, grandmas, aunts, uncles, we usually have a few siblings in there'. This includes training in strategies to manage behaviour and communication, but also in other roles as well, as Ruby, a service provider, explains:

[We] also teach the parent how to be an advocate for their child across different settings [such as early education and care and school] [...] So they can go out to the school and talk about you know, putting in visual supports or working with the school to develop an individual program. Because when they leave our program we want them to have as many skills as we can possibly teach them for when the child transitions onto Year 1. (Ruby, service provider, WA)

Although there are many differences between the approaches offered by the different service providers we interviewed, all agree that parents and families have a significant role to play in being their child's 'therapist'. One important point of difference between ABA and other approaches is the extent to which parents can be therapists outside of a specific, supervised program. ABA promotes a program of at least 15 to 20 hours per week, delivered by a trained therapist or a parent under the supervision of a trained therapist. In contrast, non-ABA service providers argue that a prescribed number of hours per week of manualised intervention may not be necessary if parents can change their day-to-day interactions with their child to incorporate principles of behavioural interventions. This argument is made by Nina, who works at a hospital and supports parents after diagnosis in getting treatment:

That question [of how intensive therapies need to be] is difficult to answer because when we talk about the research recommendations, early intervention, so that's 20 something hours, that includes everything. So how much the parents are doing it if you've got like two hours like therapy ... like formal therapy sessions, and plus the parents are doing everything every day, then it may be enough. (Nina, service provider, NSW)

A similar argument is made by Trisha, who works at an early intervention service:

I mean a lot of families are really, have honed into this 'oh, my child's got to have fifteen to twenty hours a week "because they've got autism"'. [...] What the reports don't say is that that fifteen or twenty hours doesn't have to be in an early intervention service, it's what you're doing with your child. And we work with families to try and develop that understanding. (Trisha, service provider, NSW)

Whether parents are involved in an ABA program or a different approach, it is clear that the role that many of them take on in their child's therapy is extremely time-intensive and demanding. This involves behaviour management and reinforcing desired behaviours, as described by Maddy and Shannon:

Well, it's constant. You never really stop. I don't allocate specific times. You know we always stop him in his tracks if he's doing something wrong and, you know we're always talking and doing the right things with him. We never really ... you never really stop. (Maddy, parent, WA)

[W]hen you go to the OT ... I mean it's not her working with [the child with ASD] it's you. She basically trains the parents [...] She'll sort of guide you to doing what you should be doing, but you take the active role in his therapy. So yeah I think that's just been great as well because I suppose they respect you as you're the specialist because no-one is going to know your child as much as you do. (Shannon, parent, WA)

## Summary and conclusions

### Costs

The costs of ASD to families vary. They can include private services for assessment, diagnosis, treatment and case management; modifications to the home; travel to treatment settings; and nutritional supplements and food. These costs are often compounded by the withdrawal from the paid workforce by at least one parent due to the time and resources necessary to be, as Mavis describes it, a 'taxi service—parent—therapist'. Our interview participants had made considerable financial sacrifices to ensure that their child received therapy, which is typical of parents of children with disability. Even so, waiting lists and the costs of some services meant that at least two children spent some time after diagnosis not getting any treatment.

I have called around for like an ABA program [...] and the price is outrageous and we could not afford it. So for a little while, for about six months, [child's name] was not on any program at all. (Pia, parent, Qld)

Just as it seems critically important that families have options for intervention while waiting for intensive, individualised services, it is also important that costs do not prevent children getting treatment. The Helping Children with Autism package was welcomed by clinicians and parents as an important measure to ensure that

children do get treatment; however, the capacity of the service system to deliver treatments is also limited by factors other than cost, such as the number of therapists working in an area. In many areas demand for services outstrips supply, for both low-cost and privately-funded treatment.

### *Waiting lists*

Long waiting lists are a common experience for people with a disability and their families. The diagnosis experience can be fragmented and distressing for parents of a child with ASD, and this is compounded if families then have to wait for treatment. The availability of private, expensive ASD-specific therapies such as ABA can also increase rather than relieve parents' confusion and anxiety. Many parents find it disabling to feel that they are doing nothing to treat their children's ASD, and empowering to feel that they are actively treating it (indeed, the capacity of ABA to empower parents recurs in our interviews almost as frequently as improvements to children). Waiting lists are especially critical for young children with ASD because of a convergence of factors: the availability of funding and support for children aged less than 6 years old; the importance of intervening early to ensure a positive start to school; and the importance of changing behaviours and patterns of communication behaviours before they 'escalate' and become entrenched.

Waitlist options are therefore very important for those families who do not take up ABA, which can be started immediately after diagnosis if families have sufficient resources. Children who cannot speak and those for whom playgroups are distressing should not be referred to supported playgroups. However, some children and families do find playgroups and similar models of intervention helpful, although parents, service providers and clinicians all agree that individualised treatment plans are essential. Playgroups may be helpful in part because they put parents in touch with other parents, who are often a source of support and information. Whether or not they use playgroups, parents need information and support to introduce therapeutic techniques into their daily interactions with their children, for example, to encourage and teach communication skills and manage difficult behaviours such as tantrums.

### *ABA*

Several parents reported wanting to know more about ABA than the health care workers with whom they had contact would tell them. A number reported being frustrated at the reluctance of their paediatricians to recommend ABA, and a couple describe being angry now that ABA is not the only recommended treatment.

However, the evidence from one parent, that she was told to take up ABA rather than a place in an educational setting and she regrets taking that advice, suggests one reason why health care workers may be reluctant to recommend ABA or any one specific treatment.

Clinicians and service providers may believe that it is inappropriate to recommend ABA to parents who cannot afford it, or who could benefit from other treatments. As a service provider from Queensland put it:

I guess we are aware that some of the options are quite costly and we're a little cautious I think about, again how we provide that information because we don't want to put parents in the situation of feeling like, 'I must have this, but I'm going to have to mortgage my house for that'. (Lassie, service provider, Qld)

ABA is so expensive that many parents will not be able to participate in either a centre-based or home-based program with trained therapist. It is important that the choices of parents who pay for ABA, and the decisions they often make about selling property or drawing on superannuation to do so, are recognised and honoured. This includes timely and accurate information about ABA and its appropriateness for their child and family; and the ability to choose ABA as part of an overall treatment program, rather than having to decide between ABA and another approach. However, those parents who cannot make the decision to pay for ABA also desire the best treatment for their child. It seems unrealistic to characterise parents as consumers making a choice between different treatment options that have different costs. Parents do not want to be forced to make a choice between treatments when they do not fully understand different approaches and their child's needs. Moreover, availability of different treatment options varies significantly between areas, and the costs of some treatments are well beyond the reach of many families.

### *Parents' role in treatment*

Typically, parents of children with disability expend significant energy and resources to assist in their child's treatment. They become 'lay experts' in the possibilities for their child's treatment and future wellbeing, and become advocates and even activists for services, schools and community inclusion. When a child is diagnosed with ASD, parents often take on a role as therapist in addition to these roles, either by following a manualised, highly structured program such as ABA, or by incorporating the principles of other treatment models. Parents also take on the role of case manager, albeit reluctantly.

Parents need considerable material and social resources to take an active role in their child's treatment. The families we recruited for interview in this study may be atypical in this regard: we recruited via peak bodies and parent organisations, and it is possible that the most active and engaged members responded to the invitation to participate in research. Nonetheless, even a relatively minimal treatment approach requires parents to find and assess therapies; coordinate treatments and monitor their child's progress, in consultation with one or more doctors; find and liaise with EEC services and schools; and assist their child to communicate and behave appropriately in public places and at home. Therapeutic approaches often encourage parents to change the vocabulary they use to communicate with their child, and their response to their children's behaviour, as part of their routine interactions with their child. Families who struggle to find appropriate support in one or more of these areas, and those facing additional challenges, are likely to find the experience of ASD especially difficult.

## **5.4 Informal and peer support**

Families with a child with ASD may become increasingly isolated from their community, due to the behaviour and distress of the child in public spaces. One parent may have to reduce their hours in paid work, or cease work altogether, thus increasing their isolation (Benson 2006). The family's activities can end up revolving around the child with ASD (Gray 1997). While there is some evidence of parental stress being related to the severity of symptoms of the child, there is also evidence that these can be alleviated somewhat by informal social support (Benson 2006). Informal support has far greater impact on relieving stress in mothers than fathers (Krauss 1993). Since the majority of primary carers for children with ASD are mothers this can be an important factor in alleviating stress of the family as a whole (Krauss 1993). Stress is caused by concerns of the permanency of the condition, the antisocial behaviour of the child and very low levels of social support for families with a child with ASD (Sharpley, Bitsika & Efremidis 1997). Parents of children with ASD suffer from considerably more stress than parents of children with other cognitive impairments (Boyd 2002).

Informal support is defined as a network of people consisting of family and friends or a wider group such as other parents of children with ASD (Boyd 2002). One study found that the most effective informal support for mothers was her spouse, her own parents and other families with a child with ASD (Konstantareas & Homatidis 1989b). Bristol (1984) similarly found that the spouse and parents of the mother were the most helpful.

Although the focus of this research was families rather than parents, only two parents were fathers. This could be in large part because mothers tend to take the primary carers role while the father goes out to earn the money to pay for the treatments. Most parents seemed to make decisions together and the main source of support for each other. Four mothers spoke specifically about the support their partner provided. Maddy, a mother from Western Australia, described her partner as 'her rock' and that 'they were both in this together'. They discussed therapies and what was required with each other. Maddy's other children were also very good at developing her son's imaginative play.

Two parents spoke of their partner being in agreement but leaving most of the decision making up to them. One father said:

I have to go and pay the bills. So we both find it very difficult in different ways. I find it difficult because I'm not there to help and avoid him when I am there. (Bruce, parent, NSW)

Grandparents are often involved in assisting with families. Five families in this research mentioned the support that grandparents provided. For example, Martha cites her mother-in-law as a source of support, offering respite in the way of babysitting. Using grandparents for respite or babysitting so the mother can work or study appears to be the main involvement.

Friends are often a source of informal information. Friends and socialisation were seen as part of the validation process, particularly on where to go for more formal support.

In areas where no formal networks occur parents are getting together to create their own support networks. In Victoria the Brimbank Autism Angels have established an electronic chat room. They also meet once a month to allow their children to socialise and to chat. They have also produced their own guide to ASD support including financial assistance. The guide includes a list of paediatricians, speech therapists and so forth who are experienced with children with ASD. One parent interviewed commented on a need for an Australian chat room.

### **Siblings**

Younger siblings of children with ASD are strongly impacted in their social and communication skills (Goldberg et al. 2005). Siblings of children with ASD appear to show more problems with social development. In particular, brothers of children with ASD appear to have greater problems of adjustment to their sibling's behaviour (Hastings 2003).

While this research did not cover sibling behaviour in any great depth, there were reported incidents of siblings creating problems in order to get their parents attention. Alyce reported:

I have two sons on the spectrum but my problems are with [my daughter] who is really giving me a hard time.  
(Alyce, parent, Vic.)

However, Alyce is turning her daughter's innate bossiness into a positive force by getting her to 'force' her brothers into imaginative play including tea parties. Alyce claims her daughter has become her brothers' main therapist.

Many families expressed considering whether to send their child with ASD to the same school as their typically developing sibling. Parents considered whether their child who did not have ASD could protect their sibling from bullying and act as 'eyes and ears' for the parents. Other parents were concerned that the sibling had the right to schooling away from the child with ASD.

She's [typically developing daughter] quite an emotional child at the best of times. She's very quick to get upset, particularly she found it very upsetting when these boys were picking on [her brother with ASD]. She took that very hard. I thought she would probably benefit from having her own school. (Mia, parent, Qld)

Pia is a mother based in Queensland who is concerned with where to send her son and her typically developing daughter to school:

I'm still trying to sort it out, whether it's the best thing [...] to send them both to the same school or different schools. And if it's different schools how I'm going to manage to go you know north, south and trying to work as well.  
(Pia, parent, Qld)

Several families reported positive interactions between the child with ASD and their siblings. This appeared to be particularly among families where the child with ASD did not have any unacceptable behaviour, or do not prevent the family going out as a group.

[T]hey love him to bits [...] They don't really quite understand what [ASD] is at the moment. They know that he just needs sort of extra help. (Maddy, parent, WA)

Other parents are well aware of the additional attention a child with ASD requires and make special time with their typically developing children. In-home respite, as offered in Western Australia through the DSC, for example, can offer the family a chance to act as a typical family.



[A] care worker comes out on a Saturday morning for us, so I can take my son [sibling of child with ASD] out with just him and his dad. We can sit down at a restaurant and have lunch, whereas we can't do that with our other son. (Mavis, parent, WA)

None of the families interviewed had older siblings of the child with ASD, and therefore possibly more aware of their siblings' differences. Problems associated with this may emerge later.

### Formal support

Formal support, defined here as contact with other parents through formal organisations (Boyd 2002) is recognised as an important source of information and advice. 'Someone To Turn To' is run by Autism Spectrum Australia (Aspect) NSW, which provides telephone support by matching newly diagnosed parents with a parent who has had similar experiences. Autism WA provides 'My Time', and Autism Queensland runs support groups designed specifically for parents to meet and share information. My Time groups have also been established through autism-specific early intervention centres in Queensland. The importance of these groups should not be underestimated as a source of advice and support from other families who have been through the same experience.

These support groups have provided invaluable support for families, especially in the assistance of independent information on therapies and therapists. An early intervention centre in Queensland runs regular monthly meetings for parents to keep its parent body up to date with information on financial support for ASD as well as research information.

Ruby explained their My Time sessions:

We have a lot of parents come because they've got the two hours and they have a coffee and a tea. And then we get [parents of newly diagnosed children to attend] those groups to meet parents that are already accessing services that might be a year or two ahead in their diagnosis. And so, then we get all the parents to share phone numbers and link in with each other. (Ruby, service provider, WA)

Mabel, a mother from Queensland, describes My Time, which is run through an ASD early intervention program, as a way parents can share 'the same worries and the same challenges each day'. This sort of support allows parents to seek advice from other parents who are experiencing similar problems.

[J]ust to be able to find out about how they feel about different approaches and what's worked for them and so forth. (Gina, parent, Vic.)

The My Time program also allows parents, particularly mothers, with a chance for relaxation. My Time, together with Carers WA, assists with funding for mothers to go on weekends away as a group.

My Time groups for father are apparently less successful. Autism WA have tried running such programs but they closed from lack of support, according to a service provider. However, My Time program in Queensland runs more successful programs for fathers based around purely relaxation activities.

The support groups that parents find most helpful are based specifically around ASD. Alyce has found such groups vital and her main source of support:

And I think that's been most helpful in the sense that we all know how hard it is to be dealing with children with issues when we have a partner who's not really on board. So I suppose that's been my greatest source of support. (Alyce, parent, Vic.)

Service providers also found that parent-to-parent support was fundamental to supporting families.

I mean time and time again, people say being able to talk to other parents and swap experiences and information is just invaluable, really important. I've done a survey at work around that just recently and that came out time and time again. (Katrina, service provider/parent, NSW)

I can remember a mum cried in our very first session and said that it was the first time in four years that she had sat with another parent who didn't judge her. And that when she was telling the story about her child's meltdown, that the other mum was just nodding her head going me too, me too. (Nancy, service provider NSW)

Parental evaluation of services can provide a perspective that service providers, however good, cannot give.

Regardless of how parents are connected to one another, peer support is important source of information and advice. The experience of other parents who have a child in close age and with similar problems is particularly useful, especially when making decisions about which school to choose, which therapist is most appropriate and how to deal with specific behaviour problems. For example, Lee was already a member of an organisation for parents of children with disability when she first suspected her child has ASD, because he had a prior diagnosis of Down syndrome. She contacted other parents via that organisation:

[The organisation] is made up of a group of parents and they've all got children with disabilities. So I sent an email saying, does anyone know of [...] a good paediatrician that could diagnose autism. (Lee, parent, NSW)

Shannon only found out about a disability family support agency in Western Australia through other families:

Services that could provide me with help and provide me with support like [agency] I didn't know about and I only ended up finding out about it through talking with other mums who had children with disabilities. (Shannon, parent, WA)

Vicki described her positivity regarding her son's progress and that she 'is doing the right thing':

But you know that confidence has come from other parents mostly. (Vicki, parent, WA)

Vicki proposed that a helpful strategy would be 'buddying' a family with another, immediately after diagnosis, to assist with reducing the feeling of being overwhelmed.

## 5.5 Families with complex needs

Families who do not live near services, have few resources or who have other problems to contend with (for example, a spouse with Asperger's Disorder) are in even greater need of support and case management. Often these families suffer from even greater isolation and find the diagnosis of ASD overwhelming. Families who experiencing other crises are likely to experience difficulties in effectively treating ASD, as this requires considerable resources. Nina, a service provider from New South Wales, said that these families were less likely to get intervention:

There is a crisis situation in the family, there's like separation of parents or there are other issues. (Nina, service provider, NSW)

Most of the families we interviewed had made treatment of ASD a priority (often at considerable cost) but parents, service providers and clinicians were able to talk about families who face greater than usual difficulties in doing so.

### *Families with low income and families in poor neighbourhoods*

Families in poverty or with low income are particularly disadvantaged by ASD. As some families commented, treating ASD is expensive. Carla, a clinician from Victoria, commented that she works in disadvantaged communities:

[M]ost of those families can't afford private therapy services. And neither can they afford, I mean, some of the public early intervention programs have to charge term fees of maybe \$120. Now some families can't even afford that, so it's really important I guess to explain that. (Carla, clinician, Vic.)

Carla also explained that private therapists do not tend to work in disadvantaged neighbourhoods, so even families who live in those areas and have the resources to pay for therapy may not be able to do so:

Part of the other difficulty is that families might [...] re-mortgage their houses, cash in their superannuation, do all sorts of things in order to fund a particular therapy that's not available through the public system. But, even if they can afford private therapy, the difficulty in [this area] is that there are very very few therapists working in the private sector [...] there are a number of the private therapists that I would recommend who have closed their books because they are overwhelmed with numbers. (Carla, clinician, Vic.)

### *Geography*

Geography and distance from metropolitan centres can play a significant role in the experience of families with a child with ASD. This is because location has been shown to make a difference in when children get diagnosed. The diagnosis of ASD in children is 0.4 years later in children living in rural areas than urban areas (Mandell, Novak & Zubritsky 2005). Location also matters because metropolitan centres tend to be better served by health and human services than places outside cities. Mandell, Novak and Zubritsky (2005) found that a critical mass of children with ASD was required to develop familiarity with ASD among health care professionals.

For this research no rurally-based families were interviewed; however, families who had to travel considerable distances for treatment and support were interviewed. Most of the families interviewed living outside a major city were based in regional centres and outer metropolitan areas such as Campbelltown in New South Wales or Mandurah in Western Australia. The lack of choice of service provider was mentioned by some families in regional centres. There is frequently only one major service provider and they will tend to have large waiting lists.

So there's only one person that has got the autism specific training in the private speech therapists and the private speech therapists, most have closed their books. We recommend that families access community health but community health, for speech therapy, has got an eighteen month to two year waiting list. (Nancy, service provider, NSW)

Many service providers travel from a major centre to provide support. This has the disadvantage of a large amount of time being spent travelling for possibly only one family consultation. Often these services have a very limited staff. Yet as Rachel, a New South Wales service provider, said: 'Regional families are desperate for support'. The state peak bodies Autism WA and Autism Queensland are both planning regional support teams which will travel out to rural areas a few times per year. Aspect, the state peak body in New South Wales, runs courses for parents in Northern New South Wales and recently over 100 parents participated.

Service providers interviewed from Autism WA said they are hoping that additional funding to families will allow it to provide improve services to families in remote areas. It is not unheard of for families to move to get access to more services and support. Ann, a mother now living in Queensland, was living in rural Victoria. She was offered only a few hours a fortnight of early intervention, which she knew was inadequate for her child, and she moved to Queensland to enrol her child in intensive therapy:

My son would need to be placed on the waiting list, and that when he did get into [country Victoria service provider] the most they would be able to offer would be one half hour of speech therapy a fortnight, and one two hour group session a month, and maybe one OT session a month. (Ann, parent, Qld)

Nancy, a service provider in regional New South Wales is finding that families are moving to be near them to get some sort of support because 'in regional areas, there are not any autism services with autism specialists for them to access'.

Families travel regularly to major centres to get support.

So we had [a mother] who had boys at boarding school in the city, and she used to drive to [service provider] every fortnight, and she would come in here and get guidance and go back to the farm, and she was with him all day every day as his main therapist. (Katrina, service provider/parent, NSW)

Now this mother lives in town while her husband runs the farm. One family travelled more than 100 kilometres per week for therapy while another family travelled 60 kilometres per day to access suitable early intervention.

So we drive from one side of the city, I'm talking thirty kilometres, to get him to kindergarten and thirty kilometres back just to get him to a kindergarten that's appropriate to his needs, because we don't have one in our local area. (Steve, parent, Vic.)

One family in outer Perth had to cease visiting Autism WA as the child was too distressed by travel. They have found that the \$6,000 per annum is not useful as there are no service providers in their area.

Autism-specific support in the early years is patchy at best outside main centres. Families are typically offered general early intervention support in the form of playgroups where families can discuss particular issues with the staff on site. These centres do not generally have autism-specific staff on site.

Remote access to support via telephone and email has its own problems as the service provider cannot easily assess the child remotely, and the additional support the child needs may not be available in their area.

Sometimes why families are finding it hard to navigate the system in [rural] areas is that they don't actually have those services existing. (Nina, service provider, NSW)

If the parents can afford it the only intensive autism-specific option for them may be ABA with the main caregiver running the therapy.

[W]e have four families [who] drive in once a month, we tell them what to do, give them a stack of new programs, off they go home. Not an easy option for them but better than getting nothing. (Katrina, service provider/parent, NSW)

In Western Australia, Autism WA is working with the Disability Services Commission to provide support to rural families. Ruby describes what is planned:

We're going to set up parents with Autism Pro<sup>5</sup> and web conferencing and ongoing contact with clinical staff that are based here that will also go out and do regional training. (Ruby, service provider, WA)

### *Families from non-English speaking backgrounds*

Pia's parents initially refused to believe her son had ASD.

[C]oming from the Asian background everyone said the boys don't talk until 5, [that he is being] naughty because that's just boys. Yes, so it took them a long time, about six months or so to accepting that yeah, okay something is not right with [son]. (Pia, parent, Qld)

Diana highlighted the problems of sensitivity when needing to use a translator:

Families aren't happy to use the interpreter because the interpreter's often someone within their community and they don't generally like that. (Diana, clinician, NSW)

However, Nina said that the language backgrounds of families were not of themselves significant to most families' experience.

### *Families with children with more than one diagnosis*

Children with ASD are also diagnosed with other disabilities, most commonly epilepsy and intellectual disability (although the proportion of children with ASD and intellectual disability may be less than previously claimed) (Edelson 2006; Tidmarsh & Volkmar 2003). Very few children in this research had a confirmed diagnosis of an intellectual delay. This may be because tests for intellectual disability are not normally carried out until the child is approximately 4-and-a-half years old, and the children of most of the parents interviewed were not that old.

Where a child has multiple disabilities the family can appear to be in crisis a lot of the time. Bruce, for instance, has a son with ASD, ADHD and ODD. He feels they are referred on all the time and do not get any specific help with his son's behaviour:

He was diagnosed with high functioning autism, suspected Asperger's [disorder] with also fair elements of ADHD and ODD as well. The problem we're having at the moment is finding help with the discipline side. And we've been referred back to the psychologist who arranged testing for some more assistance. (Bruce, parent, NSW)

Alyce has two children with ASD, and her husband has also been diagnosed with Asperger's Disorder. Her elder child is 8 years old and has anxiety attacks and can be aggressive. He has been prescribed risperidone, an antipsychotic medication typically used to treat adolescent schizophrenia, for his aggression:

We had a really major behavioural crisis with [eldest son], and it was before we started on the risperidone. So we were having some major aggression, and I really reached the point where we couldn't calm him down and I didn't know what to do, and the psychiatrist's voice mail said, 'I'm on holidays at the moment. In case of emergencies contact your local hospital'. And I went, well that's actually really helpful isn't it. (Alyce, mother, Vic.)

Two partners of parents interviewed and one parent interviewed had been diagnosed with Asperger's Disorder themselves, as adults.

Effective treatment can make a major difference. This was Josie's experience, whose daughter has ASD, global development delay and low muscle tone. By implementing a multitherapy environment, Josie has noticed a huge improvement with her child, including the ability to socialise and she is quite 'the social butterfly now'. By using a dedicated service provider and the Hanen program of pictorial communication, Josie is looking forward to her daughter having a life of 'working, possibly living independently and maybe even getting married'.

### *Single parents*

Four of the parents we interviewed identified themselves as single mothers. Of those, two attributed their separation to their child's diagnosis.

I'm by myself with my son. I was married, but my husband and I, we've split up, because my husband ... oh my goodness. He just can't handle my son. The stress of it. (Michelle, parent, Qld)

There is much written on parental stress and parental depression due to having a child with ASD (Bebko, Konstantareas & Springer 1987; Gray 1994); however, this appears to be intensified if the parent is single and appears to have few support mechanisms (Wolf et al. 1989). Single parents may be unable to navigate the maze of ASD and end up with insufficient therapies for their child.

Receiving a diagnosis could be a relief for mothers, proving that it was not 'bad' parenting but actually something wrong with the child. However, some fathers could not cope. Jill and her husband separated at the time of diagnosis but she is hopeful that he will return. She uses an early intervention service that allows her a break from caring but feels intensely ambivalent about this as it seems to be making her child's behaviour worse:

The hardest thing for my husband is that [child's name] doesn't like him touching him, so that makes it hard because he can't get the cuddles and stuff like that [...] I generally feel like the worst parent on the planet. (Jill, parent, NSW)

## 5.6 Prior-to-school education and care, transition to school, and school

This section describes the experience of children with ASD and their families of negotiating prior-to-school and school experiences, including EEC services such as long day care and preschool, specialist disability schools, and services to support children with disability in generalist education settings. As educators and teachers are often the first people to recognise delays and difficulties in children, these services are often central to families' experience of the transition to and around diagnosis.

### **ASD early intervention in prior-to-school settings**

Early intervention programs for children with ASD provide intensive educational therapy prior to the age of 4 years. Stahmer (2007) identifies the requirements of a good program as:

- ▶ the earliest possible start to treatment
- ▶ high treatment intensity (20–30 hours per week)
- ▶ ongoing, systematic assessment, which leads to intervention choices
- ▶ strategies to promote generalisation of learnt skills

- structured environment with a predictable routine
- high levels of staff education and training
- active, sustained engagement of the child
- individualised treatment programs designed to meet a child's needs
- specific curriculum content with a focus on communication, social/play skills, cognitive, self-help and behavioural issues
- high parent involvement.

Stahmer's research shows that there is broad agreement between ASD service providers that a multidisciplinary approach, which combines speech with behaviour and social skills development, is the ideal for children in early intervention. The delivery methodology of these supports was not as important as the consistency of delivery. These findings are consistent with Australian research (Roberts & Prior 2006).

Many parents access specialist support through ASD-specific multidisciplinary therapy services such as AEIOU in Queensland or Autism WA, therapy-specific services such as ABA, or short courses on early intervention such as Building Blocks as run at Autism Spectrum Australia (Aspect) NSW. Families may access one of the specialist services as well as a mainstream kindergarten or, as in the case of AEIOU, send their child there for up to 25 hours per week.

Multidisciplinary approaches to early intervention have the advantage of 'weaving everything into an everyday program', as described by Mabel, a mother from Queensland. Even though this is an ASD-specific program, the aim is to transition most of these children into mainstream school. All parents of children receiving multidisciplinary early intervention reported that their child was showing improvements in communication skills and social skills.

[Child] is thriving; it is just an amazing centre. [H]aving the occupational therapist and speech therapist under one roof and the speech therapy and occupational therapy and everything weaved into the everyday program.  
(Mabel, parent, Qld)

By using a dedicated ASD-specific early intervention service there is usually regular assessments of the child's progress occurring. Assessments range from one-on-one observations through to group work and whether the child is able to generalise that skill.

Transition to school is a primary focus of specialist early intervention services, as it is of mainstream EEC services.

We have backward mapped the early years curriculum, kept the same framework but backward mapped it so it caters for kids who are two-and-a-half who have autism [...] When children leave here we can map them on the curriculum so when they go into a prep class the teachers are very clear on where the children are at. (Sophie, service provider, Qld)

Parents who had their child in a general EEC service, where they had specialist in-house support or there was on-call support from an ASD support team, also reported satisfaction. For example, Maddy, a mother from Western Australia, uses a day care that has a specialist teacher's aide:

He's been there for over a year now so he's done wonderful there as well and they're willing to do as much as they can for him as well. (Maddy, parent, WA)

Maddy reported that that Autism WA provides support to the kindergarten and they are able to discuss strategies and techniques with Autism WA.

### **Generalist early education and care**

The experience of EEC is an important step for all children. It prepares them for school, teaches them independence from their parents and how to socialise with their peers (Irwin, Siddiqi & Hertzman 2007; Press 2007; Sylva et al. 2004). One study from the US indicates that children with ASD had a higher rate of

attending preschool than their peers, but that the rate of expulsion of children from even state-funded pre-kindergartens was significantly higher for children with behavioural problems (Montes & Halterman 2008). The study showed that 39 per cent of all families with a child with ASD experienced a modification in their work patterns due to problems with child care arrangements.

One recent study (Grace et al. 2008) of the experience of families with children with disability of negotiating EEC found:

- ▶ the families' primary goal was a welcoming centre that would accommodate their child, but most families were rejected from an average of five centres before finding an inclusive setting
- ▶ there is little training provided for early educators to identify concerns and possible disability
- ▶ most mainstream facilities did not fully understand the requirements of the child with a disability—parents had to fight or seek an external advocate to ensure that their child was fully integrated in to the programs of the centre
- ▶ positive experiences for families happened when parents and educators worked closely together to find solutions to issues as they arose
- ▶ successful integration was based on positive engagement facilitated by the educators; collaborative teamwork of all involved with the child's development; and empowerment of the family through incorporating them into the decision-making process regarding the child's education.

The authors recommend that additional funding should be made available to centres willing to provide for children with a disability to enable the hiring of specialist support staff (Grace et al. 2008).

Our interviews indicate that families experience a wide range of quality and accessibility of EEC services. Certainly there are some excellent early education facilities. Hayley, a parent, found that once diagnosed her son's preschool went to great lengths to become knowledgeable about ASD:

They actually said to me that when [child's name] was diagnosed it was sort of a wakeup call for them and they went out and learned about Asperger's [disorder]. And they were really good in that way so that they could deal with him and stuff. (Hayley, parent, NSW)

Juana was provided with support from her EEC service, even before diagnosis:

The ladies of the child care centre, they called someone and they introduced me to the speech therapy, she showed me how to play with him, she showed me how to interact with him. Like, even in the bath, in the shower, she helped me to [blow] bubbles with him. They cut his food in a different shape so he was more interested in colours and things like that. So, he started eating much better. (Juana, parent, WA)

Where it is possible, parents want their child with ASD to mix with normally developing children. Michelle, a mother from Queensland combines specialist early intervention with one day of kindergarten:

I sort of think it's good for him to mix with normal children, who haven't got extra issues. [...] So he can, you know, be around that [mainstream] environment and can sort of, try and learn what to do. (Michelle, parent, Qld)

The reason Sarah chose her child's preschool was that children with a disability are expected to comply with the centre's rules and procedures:

[W]e have to learn to live in the world we live in, and he can't do that if he doesn't have someone who supports that. (Sarah, parent, NSW)

Both mothers believe that this preparation is necessary before sending their children to a mainstream school, where they will have to deal with normally developing children all the time.

Some integrated centres, such the one described below by Steve in Victoria, offer the option of specialised support in a mixed environment of normally developing children and children with a disability:

[I]t's an integrated kindergarten, because they've four kids with a disability and all of the rest of these kids are mainstream ... and they just try and teach these kids [with ASD] how to integrate and assimilate within a mainstream setting. (Steve, parent, Vic.)

Michelle (a mother from Queensland) sends her child to an EEC service with a 'fantastic kindy teacher' who regularly liaises with the specialist ASD centre he attends. The provision of backup specialists makes the experience of regular kindergarten possible, as there is a place to turn to for support and advice for the kindergarten teachers. Parents who use mainstream kindergartens seem happiest when there is specialist support for the centre they have chosen. Vicki, a mother from Western Australia reported:

They [the EEC staff] know we do Floortime, they went up [to state peak body] and did some Floortime courses. (Vicki, parent, WA)

Vicki's kindergarten regularly liaises with the case manager at the state peak body, so the delivery of support to Vicki's child is consistent across the therapy sessions and kindergarten.

Many disability organisations are aware that generalist preschools and long day care centres are not able to incorporate support for children with ASD into their programming and provide specialist teams to support centres. For example, Autism Queensland and Early Education NSW and the Kindergarten Union of New South Wales provide support for centres.

They had developed a roving team ... that could go out to places like day care centres ... and help the staff there deal [with problems]. (Mia, parent, Qld)

Four parents did not experience good support from mainstream EEC services. Their experiences included the EEC service not fully understanding the needs of a child with ASD and parents having to try to fund, or find funds to pay for, extra teaching support. For example, Bernice has her child booked into a preschool for the following year, but the onus is on Bernice to find the funds for additional support staff and additional training for the existing staff:

I am fighting to put her in [name of centre]. ... [S]he can use that [federal funding] for preschool next year then we might be able to use our part of it to help fund extra teaching or resources for the preschool and also find out about the extra support and training for the teachers available because we keep getting told no-one has the training. (Bernice, mother NSW)

However, where the EEC service has the resources and commitment to accommodate children with ASD, they may also be eligible for assistance for specialist support staff.

He's still quite young and [regular EEC staff are] able to meet his needs, but we're not able to do extra stuff for him [...] The progress that we've seen since we've had extra staff [10 hours a week for 10 weeks] and he started his OT has been phenomenal, like out of this world. (Lilly, service provider, NSW)

Partly as a result of seeing improvements in the child described, Lily has organised ASD training for EEC service staff.

In contrast, some EEC services expel children with ASD because they do not have the capacity to manage behaviour.

When [son] got kicked out of day care [...] they could not take him in anymore because of his behaviour, because no-one could handle him. So they gave me short notice. (Pia, parent, Qld)

While the reason for utilising an EEC service was mainly to socialise the child with normally developing children, two mothers said it was also to provide respite for them.

I need to think what's best for [child's name] but I also need to think about what's best for me because the other four or five days a week it's just me looking after [child's name] and I have to stay strong for him. (Jill, parent, NSW)

One parent's ability to work was curtailed due to the unavailability of appropriate EEC services:

Well [husband] was due to back to work ... once [child's name] was in day care but we never got the chance. Because day cares aren't equipped for [children with ASD] either. He'd be left in the corner poohing himself. (Sally, parent, WA)



As Grace et al. (2008) found in their research the onus is on the family to research appropriate kindergartens and long day cares that are willing and capable of taking the child with ASD.

I have been to eight child care centres and preschools and this one was the only one which had a good understanding of autism. (Sarah, parent, NSW)

The concept of integrated preschools appealed to many parents. The integration allows mainstream children to mix with children with different disabilities in a supported setting.

## School

There is increasing pressure by both governments and families to ‘mainstream’ children with ASD, yet research from the UK indicates that the factors associated with successful inclusion are uncertain (Waddington & Reed 2005). UK research shows increasing concern that children with ASD are being excluded from school, with a lack of training for mainstream teachers in managing children with ASD (cited in Waddington & Reed 2005). In interviews with families of school-age children with ASD, Jindal-Snape et al. (2005) found that parents were more concerned with the ability of the teacher to manage a child with ASD, and their knowledge and experience of ASD teaching requirements, than whether it was a specialised or mainstream school.

Waddington and Reed (2005) found that many parents whose child displayed mild ASD symptoms wanted their child mainstreamed to allow them to mix in with normally developing children. Both the local authority and parents felt that peer support, teacher knowledge and skills with managing a child with ASD, and the overall school commitment to schooling children with ASD were the major factors governing successful integration. Waddington and Reed (2005) conclude that because ASD is associated with a wide range of intellectual and behavioural difficulties, an individualised assessment of whether special or mainstream schooling is appropriate is required.

The UK research cited above is largely reflected in the experiences of the parents interviewed for this research. Parents were often confused when deciding on schools. They felt that if the child had a ‘good brain’ (as described by Alyce, a parent from New South Wales) they could not be catered for in a special school or special educational unit. It appears even school principals are confused about whether special units will cater for children with high IQs, as is the case of Hayley, a mother from New South Wales with two children with ASD:

I want to look into sending him [to a special unit] which is what I have been trying to do since Year 1 but the principal wouldn't have a bar of it. It turns out his IQ is too high and the same with [daughter's] IQ is too high. (Hayley, mother from NSW)

Indeed it appeared that many children with normal or even high IQs appeared to struggle most as they did not qualify for a teacher's aide, but at the same time need additional support. Four parents expressed concern that their child was being ignored or their behaviour was unacceptable.

I think mainstream school has really run out of enthusiasm for having him there. Some days he might just sort of go to school and sit in the corner with a cushion on his head for an hour. (Alyce, parent, Vic.)

Some parents report that mainstream schools do not have the capacity or the support to manage children with ASD even though parents will try to work with the school. In Alyce's case she personally funded a teacher's aide.

The decision to choose mainstream school over a special one is problematic for many parents. Many parents expressed the desire for their child to mix with normal developing children, while other parents were concerned about the potential for bullying and social isolation that could happen in mainstream schools. Lee, a mother from New South Wales with a child with Down syndrome and ASD, sought advice from a disability early intervention service when making her decisions:

[Staff from the organisation] wrote down the pros and cons of going to a special needs school. (Lee, parent, NSW)

Other parents sought advice from their ASD early intervention service. These services appear to facilitate a happier transition process to school. Often the early intervention service will work with the school to ensure a smooth transition and will provide consultancy to the school in techniques to deal with anxiety or behavioural problems.

They are very big on transition and will actually support [son] through to Year 2. So if the class teacher has any questions they can ring [El service provider] and they'll be able to help them. (Mabel, parent, Qld)

We interviewed one parent who has recently moved from Victoria to South Australia. The interview focused on her experience in Victoria, but she also reported that in South Australia a guidance officer assists parents with deciding on the appropriate schools; however, special schools are in high demand. In Western Australia, the DSC's local area coordinators (LACs) assist in selecting schools.

We were going to put [child's name] in special school and [local area coordinator for DSC] said why? And I said because he has autism. And she made me think well why can't I? (Mavis, parent, WA)

Melissa, a service provider from New South Wales, believes parents need information on how to evaluate schools and the options available are required:

I think [parents need information] about schooling and within schools what kind of support classes there are, sizes of classes, the training or the qualifications of staff ... do they understand things like visual supports. (Melissa, service provider, NSW)

Some mainstream schools appear to cater well for children with ASD. In the example below the school has utilised visuals not just for children with ASD but those from non-English speaking backgrounds.

So the teachers there use a lot of visuals, they do a lot of visual timetabling. They are very supportive of children with particular needs. (Mia, parent, Qld)

Three parents reported that their child found the transition period between classes confronting where they had to move to another part of the school to attend music or language classes. Alyce found:

[Son] doesn't have support at that time and that's what's causing the real meltdowns ... he's run away from specialist classes and sat up the fire escape. (Alyce, parent, Vic.)

Lunchtimes were also a problem, especially for children who lack social skills. Five parents expressed fears about the potential for bullying or being overwhelmed and overlooked in a mainstream class. As this study did not interview many families where the child attended school, there was only one parent reported example of bullying, and in this case the teacher was responsible for the bullying. As, Sally a mother from Western Australia describes her oldest son who has Asperger's Disorder:

[He is] very highly intelligent, but he gets very bored and they don't have the social skills. (Sally, parent, WA)

The greatest difficulties around school appeared to be for those children with 'high functioning ASD' or Asperger's Disorder, where their behaviour could be interpreted as just non-compliant. This may become pronounced as children grow older and school curricula become more theoretical and conceptual. One service provider described it thus:

Classroom work is a lot less about interacting with concrete materials and really having to come to grips with concepts. Think inferentially, problem solve, a whole lot of other high level language based skills are a huge challenge for even very bright students with Asperger's. (Rachel, service provider, NSW)

The lack of knowledge or understanding about children with ASD within schools is improving but very slowly. As Rachel again describes it:

Although people have heard about Asperger's there's still a lot of disbelief or lack of understanding. Families are desperate for support and who say things like 'the school just won't understand, they're still trying to work out what part of him is being naughty and what of him is being autistic, how do we get through to them?'. (Rachel, service provider, NSW)

Four parents had trouble accessing funding for a teacher's aide. Even when one was assigned, the hours were limited so that a child would have several hours a week without an aide. Carla, a clinician, explains:

The state education system has very strict guidelines about the types of assessments and the types of tests that have to be done and submitted to allow a child to access extra help at school. ... The rules change often and what might be funded one year ... the child might not be eligible for funding the next year because they change the rules. (Carla, clinician, Vic.)

Steve went to great lengths to ensure that his son got a teacher's aide.

[We] have to see a psychologist [for an assessment of his need for a teacher's aide] and we give him loads of lemonade before he goes, and we deprive him of sleep ... just so the psychologist doesn't see all the great improvements that happen ... so we can get the maximum amount of a package of funding to help assist him through school. (Steve, parent, Vic.)

Seven parents spoke of choosing a small Catholic school over the larger public school as they had expectations that there would be a more supportive environment for their child. There was also an expectation that the class sizes would be smaller. Throughout the interviews parents spoke of their fears that the child would get 'lost' in larger classrooms.

Most parents who participated in our research were at the stage of selecting a school for their child. Most were expecting their child to be mainstreamed. However, they found that there was a lack of information and advice from education departments in their state regarding which school to select. Many relied on their early intervention service to advise them or information from other parents.

### Summary and conclusions

Education and the broader experience of school are extremely complex areas and were not the focus of our research. We did not interview representatives of education departments or school teachers. However, the integration of educational institutions with other services and support is extremely important to parents and families.

## 5.7 Recommendations for change

This section reports on the recommendations made by service providers, parents and clinicians to improve support for children with ASD and their families. As noted in Section 3, several of these are components of the Helping Children with Autism package.

### One-stop shop of federal and state services

There is a need for information on funding and service provision at a federal and state level. This would include:

- information on funding for intervention and equipment
- public and private services for interventions available
- educational opportunities, including special classes and special schools
- specialist programs outside school that teach children with ASD how to socialise and possibly how to play team sports
- vacation and out-of-school-hours care that caters for children with ASD who are of school age
- information on nutrition, supplements and diets that appear to improve behaviours, and scientific research available on this subject.

### Multiple access points to relevant information

Support and interventions should be described in terms of both parental concerns (for example, behaviour, communication, stigma, social isolation), **and** service type (for example, behavioural intervention, speech therapy, peer support, respite care). Access to information should be made available through a number of access points, such as the headspace website<sup>6</sup> and centres, community health centres and other appropriate centres.

### **Allied support**

Families wanted information on service providers who were used to dealing with children with ASD. These would include GPs, dentists, hairdressers and other service providers who were experienced with children with ASD. This information could possibly be available from the peak body in each state.

### **Information to GPs and baby health centres**

GPs and child and maternal health nurses are generally the first port of call for families who think their child has a problem. Although these practitioners are better informed about ASD than in the past, there is a need for GPs and health care workers to know where to direct families, even if it is a telephone hotline. Information should be available from any centre that potentially comes into contact with a family with a child (for example, Family Relationship Centres, Centrelink, child welfare agencies).

### **Development of information suitable to give parents and friends**

A brief overview of ASD and how it manifests itself should be developed. The purpose of the information would be to assist family and friends understand that the child is not naughty or spoilt and practical tips on how they can best support the family. It should include advice such as avoid giving advice based on experience with normally developing children; information about assisting children with ASD in public spaces and at social gatherings; and how to avoid increasing the child's anxiety.

### **Information on teenage years and potential problems**

There is little information on the teenage years and ASD. Parents wanted information on how to deal with potential problems around puberty and relationships. Gray (2002) in his 10-year longitudinal study that some passive children with ASD develop aggressive tendencies in the teenage years.

### **Case management**

There is a plethora of recent information regarding therapies, treatment and support for ASD. Children with ASD have a range of problems and these can alter over time. Therefore, there is a need for case managers to be assigned to each child to assist with:

- pathways from diagnosis into therapy with the ability to link them in to services
- the coordination for therapies and ongoing advice once diagnosis has been completed. This would include reviewing the plan for intervention with the parents to set priorities, modifying the plan, recommending further courses of therapies and liaising with schools where necessary
- a seamless transition into therapy, that is, options are discussed with the case manager and therapies selected recommendations regarding schooling options
- ad hoc advice as the child matures and develops different issues at each milestone of development.

### **Central coordination of waiting lists**

Information on waiting list lengths needs to be made available to parents.

In Western Australia there is an overarching body called the Western Australian Autism Diagnostic Forum (WAADF). This group was established to ensure consistency in diagnosis of ASD. As a group they also are kept up to date on waiting lists for both private and public early intervention. WAADF has managed to create a degree of cooperation and communication between services providing diagnosis, early intervention and schooling that may be a model that could be replicated in other states.

**Access to early intervention**

There needs to be access to information on what parents can implement at home while waiting for early intervention, particularly outside large cities where there is limited access to specialist therapists.

**Details of therapists experienced with ASD**

Lists of speech therapists, occupational therapists and psychologists who had experience with children with ASD are needed so that parents do not waste time and money.

Five parents expressed concern that they had spent money on a speech therapist or OT who was not skilled at dealing with a child with ASD. Yet when they had used a therapist who had experience with children with ASD it made a huge difference.

**Access to a 1800 number for support**

The telephone support could include grief counselling as well as practical advice and support. It was strongly put by one parent that the support should be for older children as well as the newly diagnosed, as this could be the time when unexpected problems occur.

**Regional and rural centres**

There is limited access to any specialist services in regional areas. In Northern New South Wales, for example, there are only two speech therapists with ASD experience. Both have huge waiting lists. More funding of ASD-specific early intervention services needs to be made available outside large cities.

**Information on schools**

Although the majority of families intended to send their child to a mainstream school, they expressed concern about finding schools that would cater for their child, with experience of ASD learning styles. A list of schools, both public and private, that are able to cater for a child with ASD was considered useful.

Two parents were not aware that they had to apply for teachers' aides the year prior to their child commencing school. This made the first year of school difficult. Information on when to apply for teacher's aide funding and transition to school preparation, including tips to smooth the transition, would be useful.

Teachers and principals need more training on planning for and coping with a child with ASD. This could include where they can source advice from as well as a deeper understanding of the child with ASD needs.

Resources are needed for schools where children with ASD are enrolled, to assist with reducing stigma, peer education and general advice on behaviour techniques.

**Funding**

The funding for ASD support appears to our interview participants to be changing all the time. Currently the funding information on the Raising Children Network website is under 'Helping children with autism'.

There is confusion over the support that is available through Medicare for therapies and the \$12,000 package for early intervention. Service providers reported difficulty in explaining the options to families. One service provider expressed concern that families were not advised on the differences in the funding and how that funding was tracked for families.

Families need to be made aware of all funding options regardless of whether they were federal or state. This should include transportation support, Carer Allowance and Carer Payment (as a family may be eligible for both the latter). As ASD is often accompanied with other medical conditions, the family may be eligible for a health care card and a number of other financial supports, depending on the child's degree of disability.

### **Autism Advisors**

Seven service providers spoke of their hope that the Autism Advisors would provide some sort of case management support for families, rather than just approving families for funding. Concern was also expressed that the advisors were employed by the peak bodies in each state. This could potentially raise conflicts of interest, as peak bodies are also service providers.

### **State funding**

Families reported difficulties in finding out what state funding is available. However, in Western Australia funding information is made available to parents when the child is diagnosed and registered with the DSC. Funding for respite options, preschool services and other support is also provided at this time.

### **Regional and rural support**

Some support is being made available to rural areas; however, it appears that investment in support outside major urban centres is inadequate. All peak bodies offer some rural support in their states. Autism Spectrum Australia (Aspect) NSW Outreach Program for schools offers support to regional schools. Aspect also runs a support centre for Northern New South Wales, which is an area of rapid population growth. However, the level of support is inadequate for the demands of that area, particularly for access to good diagnostic services, early intervention and support through the child's schooling years.

There needs to be identification of organisations that can assist with information on ASD, together with specific ASD support available to community health clinics, GPs and other service providers who are likely to be in contact with the child. Support could also build on local organisations and networks, for example, volunteer and rural organisations such as Rotary and the Country Women's Association (CWA).

### **Coordination of services and programs**

The largest concern shown by parents was the lack of seamless transition from diagnosis through to therapies. Establishing a forum for cooperation between service providers in each state may be a way of sharing methodologies and improving support to families.

As there is a lot of disparity in service approach, support levels and ongoing roll out of services in each state, it is recommended that a national organisation be established to oversee effective improvement in support for families with ASD. This agency would liaise with federal and state health, education and other services to roll out services to families. It would be charged with improving transition from diagnosis to support, as well as coordinating information provision and research into ASD and its support mechanisms.

### **Future research**

More research is required on the incidence and prevalence of ASD among Aboriginal communities, and the availability of culturally safe, accessible treatment.

## 6 Summary and conclusion

This section summarises gaps in support and promising practices, in relation to the findings.

### 6.1 Gaps in support

#### Diagnosis

##### *Lack of tailored ASD-specific programs*

As there is still no reliable scientific data proving one therapy for ASD is more effective over another (Roberts & Prior 2006), it is hard for parents to decide which method of early intervention they should use. What is clear, however, is that there are few centres that offer a one-stop shop of early intensive intervention. Apart from ABA centres, such as the Lizard Centre in Sydney, the only other intensive therapy centre for which information is readily available is the AEIOU Foundation in Queensland, which offers 25 hours per week. Both ABA services and AEIOU are relatively expensive.

All other therapies rely on heavy involvement of the parent both as therapist and case manager, and in some instances ABA is also delivered by the parent, under the supervision of an ABA therapist. These care responsibilities often preclude paid full-time work.

##### *Seamless transition to therapy*

Thirteen parents talked about being overwhelmed by the diagnosis of ASD. They were given a list of service providers and told to ring them. Families, as Ann said, are:

... told that their son or daughter has a lifelong disability, and then they're ushered out the door and they're totally left on their own as to what to do next. (Ann, mother, Qld)

There needs to be a transition process that supports families into therapy. Families are worried about which therapy to choose. They worry about making a mistake. The window of opportunity for therapy is perceived as being quite small and therefore there is an urgency to get therapy as soon as possible.

Clinicians and other diagnosticians are often reluctant to recommend specific services. They do not feel it is their place to recommend a specific provider or treatment approach. While most centres that perform diagnosis have a social worker or nurse to support the families, post-diagnosis the support they are able to give is quite cursory. Parents are often in shock and grief having just received the diagnosis and are possibly not ready to grapple with the information on what to do next. One diagnosis and assessment centre at a large hospital in Sydney provides post-diagnosis counselling and support, but their primary caseload is families and children with complex problems, such as multiple disability or family crisis. This hospital unit rings the family in a few days after receiving a diagnosis to go through options for therapy with the family.

In Western Australia there is an attempt to provide some post-diagnosis support in the provision of six lectures for parents, which covers payments, therapy options and other information. It gives families the opportunity to meet other parents going through a similar process.

#### Sources and types of information and support

There is plenty of general information on ASD. However, as described in Section 5.2, parents wanted in particular:

- information about ASD, especially treatment, prognosis and what parents can do to help
- names, details, waiting lists and costs for local ASD programs (including ABA, early intervention, prior-to-school and school programs)

- names, details, waiting lists and costs for allied health services, especially speech therapy
- ‘waitlist options’ for therapeutic interventions that can be started while children are on waiting lists for ASD programs
- some parents—but not all—want detailed research evidence on treatment efficacy.

As the majority of parents looked to the Internet for initial support, we keyed in ‘autism’, ‘autistic’ and ‘ASD’ into Google, Yahoo and Excite search engines to see what was displayed. The Raising Children Network website was not displayed on the first page of results for any of the search engines except as a sponsored Google link. Google displays for ‘autism’ include Autism Spectrum Australia (Aspect) NSW and Autism Victoria in its top four sites, top three if Australia only is selected. Excite does not show any Australian sites on its first page. The first result for Yahoo is Autism Biomedical Assessment, though it is fairly easy to get to the peak bodies in each state. The Raising Children Network is displayed in Google near the bottom of the first page if the ‘Australia’ radio button is selected from the search engine’s home page. It is recommended that the Raising Children Network increase its Google optimisation. There is a need for the website to be updated at least weekly on the availability of therapies and for the waiting lists for each service to be updated on a regular basis.

As the ASD page on the Raising Children Network website was introduced recently there was only one comment on the website by a service provider. They found that it was too complicated for families to use and they provided a subset of the information for their families.

Websites cannot deliver all the information parents want, as they want personalised information on their child. However, the Internet is, and will probably remain, a major source of information for parents. Information needs to be local and personalised, so that the parent can glean as much as is needed at the time. Information should also be positive and optimistic, so that families feel hope for their child’s future.

Information should be available in the major languages used in Australia. This model has been used elsewhere. The National Autistic Society (NAS) of the United Kingdom <<http://www.autism.org.uk>> offers information on ‘What is autism?’ and ‘Ways you can help’ in a variety of languages. It offers the email address and details of the NAS helpline and strategies parents can use at home. We recommend that information is translated into the main languages used in Australia.

The best way of imparting information, according to parents and clinicians interviewed, is face to face.

## **Treatments and the role of parents**

### *Fragmentation of services*

From this research it is apparent that most parents prefer to get all the therapy a child needs in one centre. Certainly the highest satisfaction rates appear to be with services where the therapy was interwoven with the child’s academic learning and playtime. The benefits of this are that a certain level of consistency can be expected in terms of delivery.

There are limited facilities across Australia that offer a multitherapy approach that deals with speech, behaviour and OT under one roof.

### *Case management*

Case management was seen as a huge need by families of children with ASD. This is because the information on ASD is overwhelming and parents are worried about choosing the wrong therapy. As Alyce, a mother from Victoria, said: ‘when things really get difficult there’s no-one to talk to’.

The Autism Advisors (introduced October 2008) are simply there ‘to tick the boxes’ according to Diana, a clinician from New South Wales. She said that families and practitioners had hoped they would deliver case management to families, but this has not happened, and unless significantly more advisors are made available it is unlikely to happen.



### Peer support

In New South Wales, some families in urban centres such as western Sydney are struggling with lack of support. As a result parent-run groups such as the Autism Advisory Support Services run playgroups and provide other support for families. However, this group can currently only run support groups in Blacktown and the Fairfield–Liverpool area. This group gets occasional one-off funding from the state government. We did not hear about similar groups in other areas. Similar problems are encountered in Victoria where the Autism Angels of Brimbank has been established by families to support local families with family-to-family support. It is a voluntary group and meets once a month. It receives no state funding.

### Prior-to-school education and care, transition to school and school

#### *Transitions to school*

Once a school had been chosen, most early intervention services had very good transitioning services. However, many families had trouble selecting an appropriate school. Again there was a reluctance to recommend one school over another. Most early intervention services gave the parents an in-principle list of what to look for in a school; however, there was a reluctance to recommend a specific school.

While the majority of parents had already decided whether mainstream or special school was appropriate, a few were concerned that the school would be reluctant to take their child or be able to cope with a child with ASD.

The most successful transitions appeared to be when:

- the child was familiarised with the school prior to enrolling
- additional support for the child had been arranged prior to the child starting school
- the class teacher and the principal were prepared to work with the parents to find strategies to enable the child to learn
- a good anti-bullying program was in place
- schools were not afraid to seek help from early intervention services or other support centres when required.

#### *Vacation care and out-of-school-hours activities*

While most of the families were not of school age, Juana's son is in school in Western Australia. She spoke of the holidays as being particularly problematic as there were no programs willing to accept him:

Holidays is a big issue with us because he gets really kind of bored. (Juana, parent, WA)

The following information for children wanting to engage in outside school activities was mentioned by one parent:

Like for example now he's at an age where I'd like him to do sort of extra curricular activities outside of school, and it really is just a matter of stumbling upon things to find out where there's things for kids with special needs or with additional support or whatever [...] We stumbled across a [subsidised sports] program for kids with special needs on Saturday mornings [...] So that sort of thing is fantastic. I can't really take him to like a local soccer clinic, he just doesn't get it [...] I would also [like] social skills classes and that sort of thing. (Fiona, parent, Vic.)

## 6.2 Promising practices

This section summarises the types of therapies that parents found useful, their method of delivery and the intensity. The information in this section also covers good support mechanisms including case management and peer support, both of which appeared to assist in supporting families. Both case management and peer support were seen as sources of evaluated information that assisted in making decisions on support for the child.

Our interview data suggests that effective therapies do not just 'fix' the child but also serve to empower parents, particularly where communication was established with a child who had previously been unresponsive. The fact that the child is improving also validates the decisions made by parents.

But working to get your child better means that you don't feel like, you don't feel guilty, you don't feel like you're failing, you feel empowered. (Katrina, service provider/parent, NSW)

As ASD is a spectrum of disorders it should be emphasised that what appears to be a promising practise for one family might not be appropriate for another.

## **Diagnosis**

### *Waiting for a diagnosis*

Peak bodies in all states reviewed in this study were aware of the stressful time around the period of diagnosis and were trying to provide playgroups where intervention and information could be shared with the family. The purpose of these playgroups was to provide families with tips on what could be implemented at home, such as simplifying speech and using pictures for communication. This included playgroups with a speech therapist on site who could provide advice. Examples of these are groups run by Queensland's Special Education Development Units (SEDUs), which Queensland Disability Services advise families to attend. Queensland Disability Services also supply information regarding options for therapy and advise parents to book into them even prior to diagnosis. In Sydney there are a number of playgroups for children that are on waiting lists for more intensive intervention, and in Western Australia there are early intervention services for young children, which can be accessed almost immediately.

### *Seamless transfer to therapies from diagnosis*

In Western Australia, once a family receives a diagnosis they are referred to the Disability Services Commission (DSC). The local area coordinator (LAC) for DSC acts as a case manager for the family. If the LAC is effective the family are assisted at finding the best early intervention that is available (subject to waiting lists and affordability), assisted with respite and any other services offered. When the LAC is effective the system appears to work well in assisting the family through the overwhelming period of choosing services. However, the service appeared to be patchy, in that we interviewed two parents who had not had contact with them.

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. Families have to take the initiative to contact Disability Services themselves.

Parents found case management and parental support particularly useful in confirming they were 'on the right track' or as valuable support when dealing with behaviours or what to do next.

## **Treatments and the role of parents**

### *Intensive therapies*

Therapies that are intense appear to be most effective, especially for children who cannot speak or who have severe behavioural problems. This intensity can be applied in a home setting or a centre. One of our interview participants, Diana, a NSW-based clinician, argued that a minimum of 15 hours a week is required. While ABA has the strongest evaluation research to support it, parents in this research found other therapies effective, including RDI, DIR/Floortime and, in particular, communication-based therapies including speech therapy.

Intensive therapies do not necessarily mean attending a centre or therapy session for a large number of hours. However, it does mean that the therapy has to be practised for a significant number of hours each week. This may be by incorporating the sessions within playtime or by parents implementing them as part of their normal day-to-day activities.

The most successful parts of early intervention that have appeared to work are:

- developing communication through simplifying language used with the child and making the child communicate with others (either by speech, sign language or pictures)
- implementing play skills to allow the child to learn to socialise
- developing fine motor skills through play (cutting, drawing and holding a pencil)
- breaking down activities into discrete tasks and allowing the child to master each task.

### *Intensive education centres*

Consistency is a major factor in providing a good learning environment for the child with ASD. Together with consistency, a multipronged approach to behavioural intervention was found to be most effective by our interview participants. When a child saw a speech therapist, an occupational therapist and a teacher this provided an effective learning environment. This arrangement, combined with different settings of group therapy and one-on-one intervention, appears to provide one of the most promising environments for the child to grow and learn. Examples of this in our research are Autism WA and AEIOU in Queensland, which provide autism-specific multidisciplinary therapy services. Each of these services provides a flexible approach which is built around the needs of the child.

Intensive centres that use a multidisciplinary approach are helpful for parents. The 10 parents we interviewed who attended such a centre all reported a high degree of satisfaction with it. The centre offers a mixture of group and individual one-on-one therapy. Therapies are interwoven with the child's curriculum. The centre charges \$14,000 per annum per child, although the actual costs of services are higher (the remaining costs are covered by sponsorship and fund-raising).

All the families interviewed had seen major improvements in their child's progress.

It is just an amazing centre. Having the occupational therapist and speech therapist under the one roof [...] and everything's weaved into the everyday program. (Mabel, parent, Qld)

The [centre] program that he's in now has just worked wonders, to the point he'll probably, they're saying have his diagnosis changed from autism to a speech and language impairment. (Mia, parent, Qld)

What appears to be successful in this approach is its intensity; the fact that all the therapies are interwoven into the child's day; and it provides a mixture of individual and group activities.

Intensive therapies can be offered through centres, but parents can and have implemented successful programs at home. Many peak autism bodies offer 'train the trainer' approach for parents to implement strategies at home. This can be backed up with weekly visits to the centre to check the child's progress and assist the parent in the implementation of the therapy. However, the support has to be ongoing to assist the family.

To be honest, I guess a lot of the stuff we've done at home is what really made a difference with [child].  
(Sarah, parent, NSW)

### *ABA*

ABA is controversial and not effective in all cases, but it has many supporters, including parents we interviewed who are participating in ABA programs. Steve, a father from Victoria, reported his son was diagnosed with severe ASD but did well with an ABA intensive program. The child has gone from no speech to some speech within a year.

ABA in Australia has been modified to eliminate aversive techniques and concentrate on positive reinforcement. Many families combine ABA with RDI so it is not desk-based learning but combines the principles of ABA (repetitive copying of skills, together with rewards) with play-based techniques to make it fun. A great deal of emphasis is also put on generalising learnt skills. RDI uses child-directed play to establish communication and imaginative play (O'Reilly & Smith 2008, pp. 57–59). ABA techniques are incorporated into many learning situations for children with ASD, as is DIR/Floortime and RDI, both of which are relationship-building therapies.

ABA is one-on-one intervention so has to be complemented by other avenues of improving socialisation skills. ABA is implemented in many special units in primary schools within Western Australia, which allows the children to combine ABA with group work. SEDUs in Queensland attached to mainstream schools also use ABA techniques within their service provision. We interviewed parents in Western Australia participating in this group-ABA combined program who said that it has proved beneficial to their child.

ABA is expensive to implement and the family may become the employer hiring therapists (usually psychology students) to implement the therapy in their home.

### *Communications strategies and equipment*

Often children with ASD are unable to talk and communicate, increasing their frustration and therefore increasing tantrums and aggressive behaviour. Techniques to assist parents and children to communicate more effectively are helpful for families. Often utilising these techniques can be the precursor for language development.

Speech therapy in general was perceived as particularly helpful. Eleven parents cited speech therapy as the most useful intervention. The following are additional communication techniques that parents found particularly helpful.

The **Picture Exchange Communication** (PECS) system uses pictures to communicate what the child wants to say. It is effective because it teaches that communication is a way of meeting one's needs and reduces the frustration caused by not being able to have one's needs met. The technique can be relatively simple. The child hands the teacher or parent a picture and the adult exchanges the picture for the item that is requested. PECS is often the precursor for language.

Absolutely improved and he uses PECS to facilitate it, but he's now a verbal communicator and it's just a case of setting situations up where he has to talk. (Tina, parent, Qld)

Children who are neurotypical often learn best visually so EEC settings are often fairly familiar with its implementation.

**Hanen** techniques are used in a family setting. The program 'It Takes Two To Talk' teaches the child how to interact with others using language. Parents and trainers are shown how to simplify language to improve communication.

Basically the Hanen program opened the door for me of how to get [child's name] to let me in and eventually let her father in and now she's actually quite a social butterfly. [The] best book for someone to be given when they're given the diagnosis of autism is the Hanen program book. [*More than words* (Sussman 1999)]. (Josie, parent, Qld)

**Makaton** was developed at Newcastle University in New South Wales. It is a form of sign language that incorporates signing with everyday gestures to assist communication. The parent combines signs with speech so that the child associates communication with speech. Gradually the signs are dropped as the link between speech and signs are made. Makaton also uses symbols that are gradually replaced by the written word. Makaton symbols are often used with children and adults with limited or no communication skills to prepare them for a visit to, for example, the dentist.

We started using Makaton [...] and eventually we got words out of [child's name]. And other words that she couldn't get out, she'll sign. So communication barrier was starting to ease, so the frustration and the behavioural issues started to simmer down because she could get out what she was needing to. (Josie, parent, Qld)

### *Case management*

Centres offering case management also proved to be highly successful. Eleven parents stressed the importance of case management for their child. Case management assisted in agreeing the priorities for child's interventions with the parent, confirming the child's progress and mapping out future therapies. As Ruby, a service provider from Western Australia pointed out, it was pointless focusing on writing if the biggest problem for the family was toilet training. The case manager can act as a source of information and advice for the parent.

The case manager we have for [son] is absolutely tremendous and you know I can shoot her an email on anything, she's happy to help, give me information, advice. (Vicky, parent WA)

By having regular meetings the case manager can assess progress of the child and have a significant influence on improving the parents' confidence that their child is progressing. Case managers can act as a coordinator of therapies, ensuring that the delivery of those therapies is consistent across the board, and is thus much more effective. Where a case manager was involved, it appeared that the parents were much more informed of funding options and additional support available within their state.

Case managers may come from a range of disciplinary backgrounds; for example, in Western Australia they may be a speech therapist, psychologist or occupational therapist. Regardless of their training, it was important that the person was aware of the child's history, their progress and the therapies that had been undertaken. There was also a preference for a person who had experience with issues and problems arising from having a child with ASD.

Seven service providers spoke of their expectation that the recently appointed Autism Advisors would act as case managers, but that this had not happened and that they were merely handling the access to funding in each state.

### **Peer support and access to advice**

There was a high level of satisfaction among parents who had access to on-call advice from professionals: one or more people able to offer advice and support when problems arose or the child was on a waiting list for more intensive therapy. The sense that the family was 'doing something' helped alleviate parental distress. Three parents had an occupational therapist, a speech therapist or a psychologist.

Indeed, having access to a support worker, such as the LACs for the DSC in Western Australia, seemed to provide an avenue for additional advice; for example, when deciding whether to send the child to a special school or mainstream classroom. Disability organisations in New South Wales assisted with this type of decision making.

Five parents relied on other parents for advice and support. This ranged from which therapy they found effective and which paediatrician to use through to advice about schools. Parents trusted other parents in discussing these issues, while they appeared to turn to specialists when requiring information about behaviour. Most of the parents in our research met through ASD meetings or early intervention programs. Two mothers met other mothers of ASD children through playgroups.

Programs such as 'MyTime' and 'Someone To Turn To' are run by peak organisations and other ASD early intervention services. These services are generally facilitated by the organisation. They give parents a chance to meet other parents and discuss problems with parents experiencing similar problems.

### **Prior-to-school education and care, transition to school and school**

We interviewed staff from one mainstream EEC setting with a child with ASD who said that a well-resourced centre with stable staffing can implement many of the techniques and therapies required. The director of the EEC centre was briefed by the parent on what techniques were needed. The director and the parent held weekly meetings to agree how therapies could be implemented.

This parent is fantastic, she came in and said, right this is what we're doing, this is what they want to focus on, I want to see you rolling him down the hill [...] the speech, she wants him to be pointing with his finger so it's okay to take his finger and help him because that's the precursor, [to speech]. (Lilly, service provider, NSW)

The problem this kindergarten experiences is that it is not able to give the child one-on-one time to help with specific problems. However, staff have been resourced to attend training sessions on ASD to learn about special needs education.

The peak bodies in each state have roving staff to assist educators in long day care centres and preschools in learning skills to help children with ASD.

## 6.3 Conclusion

Families with a child with ASD share much in common with other families and carers of children with disability. The experience of diagnosis is distressing and confusing, and can be made worse by fragmentation of services, inadequate support to find and assess treatment, and long waiting lists. Parents and service providers are increasingly aware of the importance of early intervention, but demand for early intervention services often outstrips supply, which means that families have to wait for the services they need, heightening their anxiety that critical periods for intervention will pass before adequate treatment is available. In many cases there is a disconnect between what clinicians and service providers say they provide and what parents say they receive; although many of the service providers and clinicians we interviewed for this project acknowledged that they cannot provide the personalised, immediate treatments parents want.

Families with a child with ASD also have experiences that are unique or felt to an unusually high degree. Both awareness and diagnosis of ASD is increasing, with ambivalent effects. On the one hand, new systems of support and assistance are being implemented. On the other hand, these new systems are complex to navigate and may not relieve the pressures on supply of treatment services that are critical to effective intervention. While recognition that ASD is a range of disabilities, with varying types and severity of symptom, is welcomed by parents who have had to fight to have their child's difficulties recognised, this heterogeneity also means that standardised recommendations for treatment cannot be made. What works for one family will be drastically inappropriate for another. Some children with ASD are verbally fluent by 3 years old, while others never gain language skills. The provision of private ABA services that are recognised as effective but not provided through the health system provides a means for some families to gain access to treatment immediately. However, many other families cannot afford ABA or find it is inconsistent with their practices and values. Intensive interventions that involve the whole family are effective, but these can require that ASD therapy plays an enormous role in a family's daily routines, interactions and even vocabulary used. Again, some families are temperamentally very suited to this, but other families do not have the resources or values to undertake it.

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 that constraints on the supply of treatment services are likely to remain and probably tighten further, 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.

## Appendix A: List of commonly used ASD therapies

Program name	Program aims	Content and format	Evaluation	More information
Applied Behaviour Analysis (ABA), or Early Intensive Behaviour Intervention (EIBI)	To manage adverse behaviours and promote prosocial behaviour. Teaches basic habits and uses an external reward system	Optimum results are found in preschool children but it is suitable for every age. Involves one-on-one intensive therapy with a trained ABA counsellor. It is very expensive and needs to be carried out over a long period.	Research Autism (see Appendix B) identified 21 peer reviewed studies: 12 showing significant improvements in children under 8 years old; six showed some limited improvements; and three showed mixed or inconsistent results. See also Lovvaas.	< <a href="http://www.autism.net.au/Autism_ABA.htm">http://www.autism.net.au/Autism_ABA.htm</a> > < <a href="http://www.lizardcentre.com">http://www.lizardcentre.com</a> >
Auditory Integration Therapy (AIT)	To address hearing distortion due to hypersensitivity	The child attends two 30 minute sessions per day for 10 days. Involves the child listening to music through headphones using certain frequencies to accustom him/her to them. Therapy is used on a wide range of ages and abilities.	A number of trials reported evidence of improvement (e.g. Edelson et al. 1999; Maddell 1999); however, all have been disputed. A Cochrane review concluded that there is no clear evidence yet for auditory integration therapy's effect on autism. Six relatively small studies met the inclusion criteria for AIT. These largely measured different outcomes and reported mixed results. The suggestion of benefit in two outcomes requires corroboration by further research using well-designed trials with long-term follow-up (Sinha et al. 2004).	< <a href="http://www.aitaustralia.com">http://www.aitaustralia.com</a> >
Building Blocks	A home-based intervention designed to equip the families to assist the child with such things as sensory issues, eating problems, communication problems and more general issues such as sibling support.	The therapies are either home based or group sessions in a centre. The format is flexible in that it is child specific. It is designed to build skills through early intervention.	There has been no scientific evaluation of this program. It is delivered through Autism Spectrum Australia (Aspect) New South Wales and is funded by the NSW Department of Education and Training and the Department of Ageing, Disability and Home Care.	< <a href="http://www.buildingblocks.com.au">http://www.buildingblocks.com.au</a> >

Program name	Program aims	Content and format	Evaluation	More information
Chelation therapy	Detoxification	Uses one or more chemicals to correct the chemical balance in bodies of people with ASD. The chelating agent is given orally, by intravenous infusion, or in the form of nasal sprays or creams.	One study indicates that use of a chelating agent may be useful to diagnose mercury levels in children with ASD, but does not recommend its use (Bradstreet et al. 2003). The British Medical Journal published a letter reporting that available information about current use of chelation therapy in ASD is scant, and what information exists implies that inappropriate agents, routes or dosage schedules of administration are being used as autism treatments (Sinha, Silove & Williams 2006). Chelation therapy has been associated with at least one death (Sinha, Silove & Williams 2006) The National Institute of Mental Health in the US has abandoned a planned trial of chelation because of safety fears (Johnson 2008).	< <a href="http://www.autismsa.org.au/html/strategies/therapies/chelation.html">http://www.autismsa.org.au/html/strategies/therapies/chelation.html</a> >
Cognitive Behavioural Therapy (CBT)	Using techniques to make the ASD person aware of how they think and how that affects others. The aim is by being aware of how they behave, the child with ASD can change their behaviour.	Using individual support, group therapy or a computer program, CBT helps the child with ASD break down problems into smaller entities that can be tackled. The therapist works on unacceptable thoughts, feelings or behaviours.	Research Autism (see Appendix B) identified 12 trials from preschool through to adults. All have reported favourable results.	< <a href="http://www.cbtaustralia.com.au">http://www.cbtaustralia.com.au</a> >
DIR/Floortime	To develop relationships with other people and develop the ability to explore sensory issues, which assists in developing two-way communication.	Using play, the parent/therapist follows the lead of the child to initiate communication and develop imaginative play. The aim is to improve relationships and communication through working at the child's pace and level.	No independent peer review of DIR/Floortime is available. Greenspan, who developed DIR/Floortime, has written extensively on it (1998; Greenspan et al. 2008).	< <a href="http://www.autismactionplan.com.au/dir-floor-time.htm">http://www.autismactionplan.com.au/dir-floor-time.htm</a> >



Program name	Program aims	Content and format	Evaluation	More information
EarlyBird	To support parents between the time of diagnosis and starting school. The program is a mixture of home-based therapies and group sessions.	Three-month long program with weekly centre-based sessions of two-and-a-half hours. It is designed to teach parents how to teach good behaviour and communication skills to the child with ASD. The program incorporates TEACCH and PECS methods.	Evaluations by the National Autistic Society (NAS) in the UK have centred on parent stress reduction and parent empowerment.	< <a href="http://www.autism.org.uk/earlybird">http://www.autism.org.uk/earlybird</a> >
Facilitated Communication (FC)	To assist children who are unable to communicate at all	A facilitator is used to assist the child to communicate using communication aides, which can either display pictures, words or letters.	No large scale studies undertaken, but small-scale studies have shown some improvement in communication ability. Systematic reviews indicate that proponents' claims are largely unsubstantiated and that using FC as an intervention for communicatively impaired or non-communicative individuals is not recommended (Mostert 2001).	< <a href="http://home.vicnet.net.au/~dealcc/facil.htm">http://home.vicnet.net.au/~dealcc/facil.htm</a> >
Hanan Therapy	To meet the needs of children with, or at risk of language delays by allowing the child to lead and using spontaneous play to encourage language development. Most beneficial in the under 5 years age group.	The 'It Takes Two To Talk' and 'More than Words' programs aim to facilitate parents' skills in social interaction with their child and to build successful communication. It does this through enhancing parents' ability to observe, engage the child in structured routines, and use natural opportunities such as household and child care tasks for joint attention during the day.	One evaluation indicates that the training course is well received by parents and has a measurable effect on both parent and child communication skills (McConachie et al. 2005).	< <a href="http://www.hanen.org/web/Home/tabid/36/Default.aspx">http://www.hanen.org/web/Home/tabid/36/Default.aspx</a> >

Program name	Program aims	Content and format	Evaluation	More information
LEAP Program (Lifeskills and Education for Students with Autism and other Pervasive Behavioral Challenges)	To support children with ASD by putting them alongside non-ASD children and training them to assist the child with ASD	Mainstream school is supplemented by learning interventions that are designed to teach behaviour and socialisation skills. Parents and other family members are also trained in behaviour intervention techniques.	Research Autism (see Appendix B) identified seven trials, all of which reported positive results.	< <a href="http://www.kennedykrieger.org">http://www.kennedykrieger.org</a> >
Lovaas	To improve communication and appropriate sensory reaction. The precursor of ABA, the program is designed to be child-directed. It starts with learning through play and the child's interests, and then the focus gradually turns to being instruction lead.	Very intensive. Commences at two years old with 15 hours per week, increasing to 40 hours per week within the year. Therapy is expected to last to at least 8 years of age. One-on-one training with a trained therapist.	One controlled study and follow-up: 19 children with autism who were treated intensively with behaviour therapy for two years were reported to gain an average of 30 IQ points, while nearly half of them were able to participate in mainstream education and were 'indistinguishable from their peers' (cf Gresham & MacMillan 1998; Howlin 1997; Lovaas 1987; McEachin, Smith & Lovaas 1993).	< <a href="http://www.lovaas.com">http://www.lovaas.com</a> >
Picture Exchange Communication System (PECS)	To teach spontaneous and expressive communication	The child needs to have semantic understanding. An individual is taught to initiate communication by exchanging a picture card for something he/she wants. The picture on the card reinforces or 'augments' the spoken word to help the individual understand what is being said. PECS is used to help the individual learn how to express his needs by showing what he wants.	Limited empirical support available. Several small studies, mostly single or small case studies, show improvements in communication (Angermeier et al. 2008; Bondy & Frost 2001; Magiati & Howlin 2003).	< <a href="http://www.pecsaustralia.com">http://www.pecsaustralia.com</a> >

Program name	Program aims	Content and format	Evaluation	More information
Relationship Development Integration (RDI)	To increase motivation and interest in social relating in individuals with ASD and to provide activities and coaching to assist them to enjoy and become competent in social relationships. Uses a series of techniques and strategies built upon the typical developmental processes of social competence.	Program is individualised and based on a Relationship Development Assessment. Once a child's relationship level is determined, an individualised program is prepared, and coaches are trained to implement the program and support the acquisition of skills.	Research Autism (see Appendix B) identified an evaluation of 17 students that showed some improvement in social relationships and independent classroom functioning. Roberts and Prior (2006) reviewed evaluation research and concluded RDI should be considered an adjunct to those other interventions that have been shown to be effective.	< <a href="http://www.autismintervention.com.au">http://www.autismintervention.com.au</a> >
Social skills teaching using LEGO	To teach teenagers how to socialise through role playing, instruction and learning how to control their emotions	Fourteen sessions are undertaken by adolescents (aged 14 to 16 years) and high functioning children in a group environment. Not suitable for children with intellectual impairments.	Evaluations (Legoff & Sherman 2006) have shown improvements in high functioning ASD children and those with Asperger's Disorder.	< <a href="http://www.socialskillstrainingproject.com">http://www.socialskillstrainingproject.com</a> > < <a href="http://autism.healingthresholds.com/research/long-term-outcome-social-skills-intervention-based-interactive-lego-play">http://autism.healingthresholds.com/research/long-term-outcome-social-skills-intervention-based-interactive-lego-play</a> >
Social Stories	To teach the child accurate information about an event or occurrence, for example, playing basketball, or what to do when the bell rings in class	Goal is to make the child understand what is occurring in each social setting. Used with children with high functioning ASD or Asperger's Disorder. Generally these children are in school.	Research Autism (see Appendix B) identified 26 scientific trials of Social Stories used with people with ASD published in peer-reviewed journals. These trials included a total of 48 individuals aged 3 to 13 years. Twenty studies reported significant improvements and three studies reported mixed, limited or no improvements. Results from three studies were unclear.	< <a href="http://www.polyxo.com/socialstories/introduction.html">http://www.polyxo.com/socialstories/introduction.html</a> >

Program name	Program aims	Content and format	Evaluation	More information
Son-Rise Program	To make the parent the teacher and work with the disability rather than against it. Uses interactive play to teach skills and educate in eye contact, social play and develop other skills	Five-day program gives parents training in five key areas. Designed for parents of children aged 18 months and older.	Findings from one published evaluation of family experiences of the program indicate that involvement led to more drawbacks than benefits for the families over time (Williams & Wishart 2003).	< <a href="http://www.autismtreatmentcenter.org">http://www.autismtreatmentcenter.org</a> >
Treatment and Education of Autistic and Communication related handicapped Children (TEACCH)	To maximise the autonomy of the child with ASD	Carers are taught the way children with ASD think, learn and experience the world. Emphasis is on visual learning. Provides a general framework for educating children with ASD.	Reported to be effective in improving self-help, social skills and communication, reducing inappropriate behaviours and enhancing the quality of life for children with ASD, along with lower parental stress rates (Van Bourgondien, Reichle & Schopler 2003).	< <a href="http://www.teacch.com">http://www.teacch.com</a> > < <a href="http://www.health.gov.au/internet/main/publishing.nsf/Content/portal-Autism">http://www.health.gov.au/internet/main/publishing.nsf/Content/portal-Autism</a> >
Triple P—Positive Parenting Program	To prevent severe emotional, behavioural and developmental problems in children and increase parental knowledge, skills, knowledge and self-sufficiency	Multilevel, multidisciplinary preventive family intervention to reach parents with varying needs. Triple P has five modules: from universal from very general media campaign to enhanced family intervention including intensive behavioural parent training with additional steps for children with disability.	Existing evidence shows that the program is effective in enhancing parental efficacy and reducing disruptive behaviour. Most evaluations of Triple P do not include children with ASD. Two studies show some efficacy for children with ASD (Whittingham 2007; Whittingham, Sofronoff & Sheffield 2006).	< <a href="http://www1.triplep.net">http://www1.triplep.net</a> >
Vitamin doses	To boost or replenish vitamin levels and/or eliminate foods causing allergies or intolerances associated with ASD symptoms	Based on theories that ASD is linked to food allergies or sensitivities. Three popular diet and vitamin interventions for autism that are frequently recommended are the casein and gluten-free diet; vitamins B12, A, D and C supplements; and cod liver oil.	No peer reviewed studies. Research Autism (see Appendix B) notes many anecdotal reports of the benefits of vitamin C from a wide variety of sources. Roberts and Prior (2006) reviewed evidence that suggested that there are reported side effects such as sensory neuropathy, headache, depression, vomiting and photosensitivity, and urges caution in the use of large doses of vitamins.	< <a href="http://www.autismsa.org.au/html/strategies/therapies/vitaminB6.html">http://www.autismsa.org.au/html/strategies/therapies/vitaminB6.html</a> >

## Appendix B: List of websites providing information on ASD

### International websites

Autism Canada Foundation	Aims to bring the latest research on treatments including biomedical and alternative medicines in a format that is readable for carers of children with ASD.	< <a href="http://www.autismcanada.org">http://www.autismcanada.org</a> >
Autism New Zealand Inc.	For parents and people with ASD or Asperger's Disorder. Includes articles and up-to-date information on therapies. The publications include articles aimed at improving police understanding of ASD.	< <a href="http://www.autismnz.org.nz">http://www.autismnz.org.nz</a> >
AutismOnline	Designed for newly diagnosed families, this international website has a strong American slant in the information provided.	< <a href="http://www.autisonline.com">http://www.autisonline.com</a> >
Autism Research Institute	A non-profit organisation dealing with current research in autism, mainly biomedical research. Some practical advice for parents including types of medication and therapies to try. Comprehensive section on current biomedical research.	< <a href="http://www.autism.com">http://www.autism.com</a> >
Autism Society of America	Information on current research, conferences, etc., and articles such as travelling by aeroplane with a child with ASD. Website also has social networking pages for families of children with ASD.	< <a href="http://www.autism-society.org">http://www.autism-society.org</a> >
Autism Speaks	ASD advocacy site for Canada and the US. Raises funds for research into ASD in the US, and lobbies media for improved understanding in the general public regarding ASD.	< <a href="http://www.autismspeaks.org">http://www.autismspeaks.org</a> >
Centers for Disease Control and Prevention—Autism Spectrum Disorders	Current, authoritative information. Resources for parents, professionals and others. Has an FAQ section dealing with vaccinations.	< <a href="http://www.cdc.gov/ncbddd/autism">http://www.cdc.gov/ncbddd/autism</a> >
Healing Thresholds	Attempts to describe therapies (including diets) for autism and lists the scientific research on each therapy available.	< <a href="http://autism.healingthresholds.com">http://autism.healingthresholds.com</a> >
International Society for Autism Research (INSAR)	Runs annual scientific meetings and publishes the journal <i>Autism Research</i> .	< <a href="http://autism-insar.org">http://autism-insar.org</a> >
Research Autism	UK charity dedicated to research into interventions in autism. Includes list of evaluated interventions and rating system of studies including medications and other treatments such as coloured glasses.	< <a href="http://www.researchautism.net">http://www.researchautism.net</a> >
Talk About Curing Autism	US-based family support website aimed at supporting parents of children with ASD with recommendations on therapies and diets.	< <a href="http://www.talkaboutcuringautism.org">http://www.talkaboutcuringautism.org</a> >
The National Autistic Society (NAS), UK	Multilingual site with information on support and services for families dealing with ASD, including research papers.	< <a href="http://www.nas.org.uk">http://www.nas.org.uk</a> >
The University of Washington Autism Center	Centre for ASD treatment and diagnosis; provides description of ASD and some symptoms. Includes list of publications targeted at parents from some well-respected authorities in the field.	< <a href="http://depts.washington.edu/uwautism/research">http://depts.washington.edu/uwautism/research</a> >

**Australian websites**

A4 Autism Aspergers Advocacy Australia	A grassroots organisation designed to advocate for more support for autism. Runs a forum on Australian Government support for autism.	< <a href="http://a4.org.au/a4/abouta4">http://a4.org.au/a4/abouta4</a> >
Aspect (Autism Spectrum Australia)	Peak ASD organisation. Provides information on diagnosis support, as well as running an early intervention hotline. Main focus is New South Wales.	< <a href="http://www.aspect.org.au">http://www.aspect.org.au</a> >
Autism Advisory and Support Group	Based in South-western Sydney, the group is focused on support for families and carers of children with ASD. Has a list of ASD-specific playgroups in the area.	< <a href="http://www.aass.org.au">http://www.aass.org.au</a> >
Autism Advisory Board on Autism Spectrum Disorders	Advises government on needs of families dealing with autism. Includes papers on the increase in ASD.	< <a href="http://www.autismaus.com.au">http://www.autismaus.com.au</a> >
Autism and Aspergers Support Club Inc	Sydney-based social support club for parents and children with ASD. One club is based in Burwood, the other in Richmond.	< <a href="http://www.autismsupport.org.au">http://www.autismsupport.org.au</a> >
Autism Association of Western Australia	Runs early intervention support for Western Australia.	< <a href="http://www.autism.org.au">http://www.autism.org.au</a> >
Autism Queensland	Runs early intervention support, TEACCH and other behaviour interventions. Centres located in Brisbane, Rockhampton and Cairns.	< <a href="http://www.autismQld.com.au">http://www.autismQld.com.au</a> >
Autism SA	Provides training and support for children with ASD, support to schools and assists with employment opportunities.	< <a href="http://www.autismsa.org.au">http://www.autismsa.org.au</a> >
Autism Victoria	An information website that includes details regarding the Autism State Plan for Victoria.	< <a href="http://www.autismvictoria.org.au">http://www.autismvictoria.org.au</a> >
Olga Tennison Research Centre	Joint initiative of La Trobe University and Autism Victoria. Intended for researchers, it aims to research into effective treatments/therapies using scientific, evidence-based methodologies.	< <a href="http://www.latrobe.edu.au/otarc/centre.html">http://www.latrobe.edu.au/otarc/centre.html</a> >

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## Appendix C: Summary of reported support services by state

This section summarises the most significant differences between the states in terms of programs, treatment and diagnostic services, as reported by our interview participants. Most of this information comes from our interviews. It has not been verified and should not be understood as an independent or systematic policy audit. It is presented here to contextualise the experience of families in the different jurisdictions.

### **New South Wales**

Autism Spectrum Australia (Aspect) NSW is the peak body in New South Wales for autism support. The Autism Advisors for New South Wales are situated within Aspect. Aspect provides a range of services from diagnosis to 'Building Blocks' early intervention support and parent-to-parent support with the program 'Someone to Turn To'. They also have a team that visits schools attended by children with ASD and provides workshops and training for teachers at no cost (the cost is borne by parents). This team also makes periodic visits to families and schools in regional New South Wales. Aspect has a branch on the far north coast of New South Wales.

We interviewed service providers in New South Wales from disability early intervention services and from a centre-based ABA provider.

### **Victoria**

There are two large diagnosis and support centres in Melbourne at the Royal Children's Hospital. The Olga Tennison Autism Research Centre (OTARC) is at La Trobe University. It was established to advance knowledge of the nature and causes of ASD, as well as to develop and study evidence-based strategies for supporting children and families.

In May 2009 the Victorian Government released the Autism State Plan with the aim of providing more integrated services. At the same time the Victorian Government announced that all diagnosed children with ASD will be eligible for additional support by the Disability Services Division of the Human Resources Department. Families can request an individualised program to be developed.

The peak body, Autism Victoria, was described as useful primarily as a source of information by participants.

We did not interview service providers in Victoria. The Department of Education & Early Childhood Development funds a range of ASD programs and services, including the Autism Secondary Consultation and Training (ACT-NOW) Strategy. This aims to build skills across Victoria to enable each network of early childhood regional service providers to provide a more integrated range of early interventions for young children with autism and their families that will complement and interface with other agencies and services; promote understanding of ASD and other developmental disorders; and improve linkages between service providers and strengthen partnerships between services and families.

### **Queensland**

In Queensland the peak body, Autism Queensland, provides both information and early intervention programs, including a centre in Cairns. Autism Queensland operates two schools where children with particular problems are pulled out of their home school for a couple of days per weeks to specifically address those behaviours or problems.

Education Queensland has a number of Early Childhood Development Programs and Services (formerly SEDU) that offer a range of services. Of these, our interview participants talked mostly about playgroups for families who are on waiting lists for therapies. Parents also talked about the SEDU as a good source of information and contact with other parents. Disability Services Queensland offers a lot of support to families with a child with ASD including advice on options available and funding options such as additional funding for communication equipment.

We interviewed parents whose children attended AEIOU centres in Queensland. AEIOU has four centres that operate full-time early education programs for children with ASD, aged 2-and-a-half to 5 years of age. The centres provide a range of services including OT and speech therapy as well as selected ABA techniques. Service providers provide assessments on the child's progress and are prepared to modify therapies as required. Both also offer parental support. AEIOU has father programs designed to get the fathers more involved.

### **Western Australia**

Under the auspices of the Western Australian Autism Diagnosis Forum (WAADF), the child is referred to a developmental paediatrician for diagnosis. The diagnosis process is multidisciplinary: the child is seen by a clinical psychologist, speech therapist, occupational therapist and paediatrician before the diagnosis is completed. The state's Disability Services Commission (DSC) is then notified of the child's diagnosis. DSC is responsible for supplying the family with information and contact details of appropriate therapists, funding availability and any other support available, such as in-home respite care. Respite care can be taken as a few hours on a weekly basis if necessary to allow the parents to do weekly shopping or attend other children's sport activities. WAADF requires therapists to provide feedback on waitlists, regardless of whether they are private or public. This assists diagnosticians as to where they send families for services. WAADF appears to facilitate a close working relationship between paediatricians, therapists and schools in Western Australia, which leads to greater cooperation and higher parent satisfaction. However, WAADF appears not to have universal coverage as we also spoke to families who seemed to receive very patchy information and support.

Autism WA acts as an information resource as well as providing programs for children and their parents.

Special education units attached to mainstream school offer programs that use elements of ABA, speech therapy and OT. The purpose of these centres is to gradually ease the child into mainstream school wherever possible by focusing on the specific areas of impairment.

As in other states, service and support appears to be largely metropolitan-based with rural and regional support starting to occur especially in the south-west corner of the state. Satellite support for remote families via video conferencing is in the planning stages and follows the investment of FaHCSIA in such services through Autism WA.



# Appendix D: Interview schedules

## Families

### **How parents gained information on treatments/therapies available**

- Can you tell me a little about your experience of diagnosis?  
(What happened? Who was around to support you?)

### **How decisions were made over which therapies to use/who assisted them in the decision making process**

- How did you decide what therapies/treatments to use?
- Who assisted you in making the decisions as to which therapy to use?  
(Experts; GP; partner/family; friends; other ASD parents; support groups)
- Have you received any financial assistance for therapies and treatment?

### **Experiences of therapy**

- Are you currently using more than one therapy/treatment? If so, which ones?
- What has been the most helpful therapy/treatment?
- What has been the most difficult therapy/treatment?
- Overall, are you happy with the treatments/therapies? Have you noticed any changes in [child's name]?

### **Gaps in information**

- Who has provided you with the most helpful information in regards to therapies and services for children with ASD?
- When it comes to making future decisions for [child's name] do you feel that there is enough information available to assist you to do so?
- What are the gaps in information that you see with future decision making regarding [child's name]?

## **Clinicians/advocates/service providers**

Topics are in bold (prompts are in brackets)

### **Referral/pathways to programs**

- ▶ After you have given a family the formal diagnosis of ASD, do you provide them with information on treatments or therapies?

(Do you do this immediately after your diagnosis?)

(Do you arrange a follow-up meeting to discuss therapies?)

- ▶ What kind of information do you provide to families?  
(Booklets, websites, information on services, support groups)
- ▶ How do they decide which course of treatment or therapy to follow?
- ▶ Do you find that families tend to follow your recommendations?

### **Availability of services through public/private health systems**

- ▶ The therapies that you recommend—are they available through public or private health systems?
- ▶ At what stage would you tell families about the sources of financial support available to them?

### **Gaps in information**

- ▶ Where are the gaps in information for families?
- ▶ Do you have any suggestions as to how to improve information for families?

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## List of shortened forms

ABA	Applied Behaviour Analysis
ADHD	Attention deficit hyperactivity disorder
ADI	Autism Diagnostic Interview
ADOS	Autism Diagnostic Observation Schedule
ARIA	Accessibility/Remoteness Index of Australia
AS	Asperger's Disorder
ASD	Autism Spectrum Disorder
AAC	Augmentative and Alternative Communication
DADHC	Department of Ageing, Disability and Home Care (NSW)
DSC	Disability Services Commission, Western Australia
DSM-IV	<i>Diagnostic and Statistical Manual of Mental Disorders</i> 4 <sup>th</sup> edition
EEC	Early education and care
EI	Early intervention
EIBI	Early Intensive Behaviour Intervention
LAC	Local area coordinator, Disability Services Commission (WA)
ODD	Oppositional Defiant Disorder
OT	Occupational therapy
PECS	Picture Exchange Communication System
PRT	Pivotal Response Training
RDI	Relationship Development Intervention
SEDU	Special Education Development Unit (Qld)
TEACCH	Teaching and Education of Autistic and Communication related handicapped CHildren
WAADF	Western Australia Autism Diagnostic Forum



# Endnotes

- 1 Sue Larkey's web site: <<http://www.suelarkey.com>>.
- 2 Refers to MBS items. Item 135 is a new item, introduced as part of the Helping Children with Autism package in July 2008: 'consultant paediatrician, referred consultation for assessment, diagnosis and development of a treatment and management plan for autism or any other pervasive developmental disorder.' Item 110 pre-exists Item 135 and is not ASD-specific: 'consultant physician (other than in psychiatry), referred consultation—surgery or hospital'.
- 3 The costs of ABA can be claimed as a tax rebate, but are not included in the MBS (Australian Taxation Office 2001).
- 4 Two of the parents we interviewed were emphatic that ABA is the only effective intervention for ASD, a claim at odds with most published evidence.
- 5 Autism Pro is an assessment and intervention package designed to be implemented by the parent remotely. It guides the family through practices they can implement at home and is supported with online seminars. Autism Pro is marketed through Aspect Autism Spectrum Australia.
- 6 <<http://www.headspace.org.au>>.



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**Post-diagnosis support for children  
with Autism Spectrum Disorder,  
their families and carers:  
older children and young people**

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# Contents

<b>Executive summary</b>	<b>111</b>
<b>1 Introduction</b>	<b>115</b>
1.1 Background	115
<b>2 Literature review</b>	<b>117</b>
2.1 Adolescents and adults with ASD	117
2.2 Interventions	120
2.3 Transition planning	125
2.4 What families find effective	129
2.5 Service provision	131
2.6 Siblings	132
<b>3 Methodology</b>	<b>135</b>
<b>4 Findings</b>	<b>137</b>
4.1 Vulnerabilities	137
4.2 Late diagnosis	140
4.3 Parents' treatment decisions and approach	141
4.4 Support for siblings	142
4.5 Post-school support	143
4.6 Information and service gaps	145
4.7 What parents find effective	149
4.8 Conclusion: summary of recommendations	152
<b>List of shortened forms</b>	<b>155</b>
<b>Endnotes</b>	<b>157</b>
<b>References</b>	<b>159</b>

## List of tables

<b>Table 1:</b>	Supports and services found to be helpful or unhelpful	130
<b>Table 2:</b>	Participant category, by state	135
<b>Table 3:</b>	Current age of child with ASD, by state	136
<b>Table 4:</b>	Time since diagnosis	136

# Executive summary

## Background

This is the final report of the research project entitled ‘Post-diagnosis support for people with Autism Spectrum Disorder (ASD), their families and carers: older children and young people’. The research was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) as part of the Social Policy Research Services agreements. This project is an annex to the 2008–09 study on young children (the main study), and addresses the following questions:

- What is the experience of children and young people growing to adolescence and adulthood with ASD? What is the experience of their parents and families?
- Do children and young people who have been recently diagnosed with ASD in older childhood and adolescence differ from those who were diagnosed as young children?
- What kind of evidence is there for the long-term effectiveness of early interventions? How do adolescents and young adults fare as a result of interventions they received when very young?
- What is known about individuals with ASD during adolescence and young adulthood?
- What is known about interventions for adolescents and young adults?
- What do families say they have found helpful?
- What are the identified current needs for service and support for older children and young people with ASD, and their families? What are their anticipated future needs?

This report is based on:

- a review of selected literature on the experience of ASD on children and their families as they grow older, intervention studies, and programs to assist transitions from school and address specific areas that are often challenging for people with ASD such as social skills
- interviews with 11 parents and ASD service providers and clinicians in New South Wales and seven parents and ASD service providers in Victoria.

A review of the literature shows that while many children who experience early intervention transition well through adolescence, there is a small proportion who find that the onset of puberty together with an increasingly complex world brings an increase in anxiety and an increase in loneliness as the adolescent becomes aware of their ‘differences’. There is a need for ongoing intervention into adulthood that focuses on developing social skills and enhances self-esteem.

Several longitudinal studies show that the outlook for adults with ASD is poor; however, there are some indications that early intervention (that is, intervention prior to 6 years of age) is having long-term benefits if there is continuing support throughout the adolescent years, with increasing numbers of young adults with ASD entering the workforce.

Behavioural interventions to address social skills, behaviour rigidity and similar behavioural issues associated with ASD have been subject to research. Social skills training (SST) involves the skills necessary for interacting socially with other people. Interventions for extremely challenging behaviour by people with ASD have been shown to be effective in some instances, and pharmacological treatments are increasingly discussed.

There is an enormous, and fast-growing, clinical literature on ASD. However, this literature gives no definitive answer to the best approach for older children and adults with ASD, as symptoms are so diverse within ASD, and the ‘fit’ for children and families of treatment modalities is so important.

Internationally, increasing attention is paid to post-school transition planning for young people, including employment services and skills in managing daily tasks.

Research on what families find effective, and the negotiation of intellectual disabilities within families, emphasise the importance of a holistic approach to families. The needs of families change over time. Conflicts and behavioural problems cannot be understood in isolation, but need to be considered as part of a functional approach.

## Findings

### Vulnerabilities

The ASD-related impairments that adolescents experience, as reported by parents, include challenging behaviour including aggression, anxiety, depression, loneliness due to poor social skills, and difficulties with school work and peers.

Four of the 14 adolescents discussed in the interviews have challenging behaviour. There appeared little support for emergency situations other than the police, who families were reluctant to use.

While aggressive behaviour was the extreme end of the scale, 10 parents spoke of poor behaviour in school or upon returning from school. In extreme circumstances this led to self-exclusion from school, with one child completing all his school years doing distance education.

Behaviour interventions that worked well in early childhood were often rejected by the adolescent, particularly in the home environment.

Fourteen of the parents interviewed highlighted social skills as their main need for their child.

Three service providers spoke about the importance of putting social skills training in place before social phobia or anxiousness took hold. One recommended that social skills training should commence in late primary school before children with ASD become aware of, and self-conscious about, being 'different'.

### Late diagnosis

The children of most of the parents we interviewed had received a diagnosis more than five years ago.

The process of diagnosis for these families appears to share commonalities with the families of young children interviewed for the main study, in that there were no direct links between diagnosis and treatment and parents needed to spend time and resources finding out the best course to take. One difference between diagnosis of older and younger children is that early intervention services tend to be unavailable for older children and in any case are not designed for them.

### Parents' treatment decisions and approach

As we found in the main study, 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. A number of the parents we interviewed were extremely engaged with their children's treatment and supporting other parents, while others described the importance of treatments fitting with the whole family.

### Support for siblings

Siblings of children with ASD often experience pressures of their own. In this study four parents reported that their children without ASD suffered embarrassment or other problems because of the behaviour of their siblings.

These ranged from being physically abused, not being able to give the sibling space to have friends over, and general noise and distraction for two who were studying for their final exams. However, two parents who had older children who no longer lived at home talked about the great bond the siblings had. Both these families used the older sibling for respite.

### **Post-school support**

Transitioning from high school often appears to be problematic. Parents also need support in future planning for their adolescent. They need help deciding which option is best for them, including whether their child will be able to live independently, options for training and employment, and assistance with planning for that time.

Senior school can be an especially difficult time for children with ASD and their parents, as the typical turbulence of adolescence is compounded by the specific challenges of ASD.

### **Information and service gaps**

Adolescents, especially those who have not had early intervention, need ongoing therapies such as speech therapy, occupational therapy (OT) and psychology. Parents with younger children can use the Raising Children Network website, but there is no one authoritative Australian website that gives information on therapies, funding and support agencies in each state for older children and young people.

Information is needed on both public and private schools, plus any details of additional support they offer, including life skills training, peer support and focused anti-bullying policies and practices.

Information about and access to a range of services was identified by parents and service providers that are particularly important for older children and adolescents, but often difficult for their families to find. They include:

- ▶ mental health services
- ▶ social skills and social opportunities
- ▶ educational and vocational services
- ▶ respite services
- ▶ crisis support.

### **What parents find effective**

Parents identified a number of services and strategies they have found effective, including:

- ▶ early intervention
- ▶ intensive and specialist services
- ▶ behavioural intervention
- ▶ drug therapy
- ▶ social skills training
- ▶ parental training
- ▶ information and support groups.

### **Recommendations**

A number of recommendations for changes to service delivery and support emerged from the literature review and interviews, in the areas of:

- ▶ behaviour support
- ▶ life skills
- ▶ social skills
- ▶ access to timely and authoritative information
- ▶ funding
- ▶ integrated education and support environments
- ▶ respite.

# 1 Introduction

This is the final report of the research project entitled 'Post-diagnosis support for people with Autism Spectrum Disorder (ASD), their families and carers: older children and young people'. The research was commissioned by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) as part of the Social Policy Research Services agreements. This project is an annex to the 2008–09 study on young children (the main study), and addresses the following questions:

- What is the experience of children and young people growing to adolescence and adulthood with ASD? What is the experience of their parents and families?
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- What is known about interventions for adolescents and young adults?
- What do families say they have found helpful?
- What are the identified current needs for service and support for older children and young people with ASD, and their families? What are their anticipated future needs?

## 1.1 Background

The main study found 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. A great deal of information on ASD is available, but parents value personalised, specific information about their own child. Parents had experienced a range of intervention types and intensities. Multidisciplinary approaches that combined preschool education with behaviour, speech and social therapies were particularly valued. Parents are often distressed in the period after diagnosis because there is no immediate or direct path to treatment, and because they often need to become case managers.

This report is based on:

- a review of selected literature on the experience of ASD on children and their families as they grow older, intervention studies and programs to assist transitions from school and address specific areas that are often challenging for people with ASD such as social skills
- interviews with 11 parents and ASD service providers and clinicians in New South Wales, and seven parents and ASD service providers in Victoria.

Diagnoses of ASD are increasing. The report on the usage of disability support services provided under the Commonwealth State/Territory Disability Agreement (CSTDA) for the year 2006–07 (2008) notes that the percentage of service users with a primary diagnosis of ASD consistently increased over a four-year period, from 8,249 people and 4.8 per cent of service users in 2003–04, to 13,308 people and 6.4 per cent of service users in 2006–07 (AIHW 2008, p. 118, Table A2.4).<sup>1</sup> This is not necessarily an indication that the incidence of the disorder itself is increasing. It is generally agreed that the increase is due to greater awareness of the condition, and also to a broadening of the definition to include more individuals at both the higher and the lower functioning ends of the spectrum (Eaves & Ho 2008).

In response to increases in the incidence of diagnoses of children with ASD, Australian governments at both federal and state levels are providing ASD-specific funding and services to children with ASD and their families. Because of the importance of intervening early with timely and intensive therapies, these government-funded services have tended to focus on the important first five years of life. For example, the Australian Government's Helping Children with Autism initiative is predominantly focused on children below the age of 6 years. There is some support for older children, delivered through the Department of Education, Employment and Workplace Relations (DEEWR), but this is mainly through professional development for teachers and information sessions for parents.

This focus on young children is not new. The families of children with ASD have been identified in the past as relatively poorly serviced by therapeutic and educational support (Bristol & Schopler 1983). The needs of these families have been recognised, and consequently there is an extensive clinical literature devoted specifically to adolescents and young adults with ASD. However, information for parents on treatment options and evidence on what families find helpful in living with ASD is less available. Many children are diagnosed when they are older than 6 years, and children and families with children diagnosed young also require ongoing support through the school years and beyond. As the numbers of children of all ages newly diagnosed with ASD continues to grow, increasing demands will be placed on schools, post-school education and training, and disability services.

This present study extends an earlier study (valentine et al. 2009), which focused mainly on children younger than 6 years of age, and shifts the focus to older children, particularly those in high school, and to those young people in transition from school to adult life.

Interviews conducted for the previous study found that government-funded support for preschool-age children was growing, both in number and in type of service, although the demand for services still exceeded supply. However, there is less attention given to support for older children, and as a consequence, it is even less adequate. Therapeutic interventions and parent training and support services are needed by children newly diagnosed as adolescents, and by older children and young people who were diagnosed as young children with ASD. Diagnostic and assessment services are also needed for older children and young people, such as those with suspected Asperger's Disorder (AS; part of the ASD spectrum), often identified for the first time in high school. Also important are specialist disability schooling and post-school education, and ASD-specific support in mainstream schools and in post-school education and training institutions.



## 2 Literature review

This section of the report reviews the literature on the trajectory of children with ASD through later childhood and adolescence, interventions for older children, and family and social support. The literature on ASD is voluminous, including at least four research journals dedicated to autism and similar disabilities: as noted in the main study, parents of children with a diagnosis of ASD are confronted with an overwhelming amount of information. It was therefore not possible, or appropriate, to conduct a full-scale systematic literature review on autism and adolescence for this project. Our search strategies included searches of the social work and sociology (as opposed to clinical) literature, and targeted searches of EMBASE, Sociological Abstracts and Web of Science databases. We focused particularly on discussions of families' and children's experiences of ASD, comparisons of children diagnosed earlier and those diagnosed when they were older (of which we found little direct information), and the needs of both children and their families.

### 2.1 Adolescents and adults with ASD

There is evidence that interventions that take place prior to the child turning 6 years of age will lead to improvements in the long term, and the earlier the intervention the more likely it is that the child will make progress. Howlin (2004) argues these improvements may not be uniform across all areas of impairment, and all the studies she reviewed found that improvements were most marked in children with higher IQs and greater verbal ability. A number of other effectiveness issues remain unresolved, including the type, intensity and duration of the intervention, the delivery (whether by parents or in a clinical setting), and what is most appropriate for older children and adolescents. Moreover, while the skills learned early in life can mitigate or even abolish some of the worst of the behavioural problems in later childhood, rarely are they the kinds of skills needed for adult life (Howlin 2004). And finally, because ASD is not a curable condition, no intervention, no matter how early or intensive, can obviate the necessity for ongoing support throughout the life course.

The policy emphasis on early intervention and hence on very young children can mean that too little attention is paid to older children and young adults (Howlin 2004), and there are few studies addressing ASD in adults (Farley et al. 2009). As a consequence, little is known about the transition of young people with ASD from childhood to the adult world, and services are often time limited to childhood or are inappropriate for adults. Yet ASD is not a curable condition, and the need for services and support is lifelong and not confined to childhood.

The natural history of ASD is, like much else associated with the syndrome, heterogeneous, and there is no one trajectory of severity or type of impairment through childhood and adolescence. There is therefore no definitive research finding on whether impairments decline or increase in severity over time. Moreover, the application of findings of longitudinal studies, which provide high-quality findings on the wellbeing of people with ASD as they age, is limited by the changing nature of ASD and the changing nature of interventions. Children diagnosed with ASD today have more diverse impairments than those diagnosed in the past, and there are more and more robust interventions around than ever before. Nevertheless, the weight of evidence from longitudinal studies suggests the need for sustained support and training for children and their families over the life course. Even though early intervention is beneficial, there is a need for support to continue on into the school years. Problems such as exclusion from school, inappropriate behaviour and bullying in the playground could be ameliorated with appropriate interventions and support (Barnard 2002).

The symptoms of ASD do improve with age for some children, even in the absence of intensive early intervention. One study found that even some basic support such as speech therapy and special education can ameliorate some of the worst symptoms by early adolescence (Eaves & Ho 1996), although all 76 of the children followed retained a diagnosis of ASD. Another longitudinal study (McGovern & Sigman 2005) similarly found that most adolescents and adults continued to meet the diagnostic criteria for ASD, but their parents reported improvements in several domains in adolescence compared to middle childhood, including social interactions,

repetitive and stereotypical behaviours, adaptive behaviour and responding to other's distress. There is also some evidence that family stress reduces as children grow to adolescence, either because the family adapts to the features of ASD or impairments become less severe. Some children who had previously been difficult became less disorderly as teenagers, and relationships with siblings and grandparents and other extended family improved (Gray 2002a, 2002b; Lounds et al. 2005). Altieri and von Kluge (2009) found that enmeshed styles of parenting (that is, the parent is heavily involved with the therapy of the adolescent) assisted with coping with the stress regardless of the behaviour levels found in the adolescent.

However, research indicates that symptoms often do not diminish in severity and children's distress and impairment may increase with adolescence as their social world becomes more complex and they become more aware of their disability (Williams White et al. 2007). The transition into high school requires support systems to help children manage different school requirements in relation to academic work and differences such as having multiple teachers. Adolescence is also a transition often fraught with confusion and misinformation as families must try to cope in the face of limited opportunities and insufficient resources. There is evidence that, without appropriate supports, rigidity and repetitive behaviours may become more entrenched (Howlin 2004). Those teenagers who become aggressive and harder to control, especially as they grow larger and stronger, are a significant problem for their families and for any school environment (Gray 2002b). Moreover, the turmoil of adolescence often coincides with the midlife transitions of mothers who are grappling with their own identity issues and experiencing difficult emotional, physical and social changes (Todd & Jones 2005; Schneider et al. 2006). Many fear that their child's adulthood will bring new difficulties, and the problem of how the child will cope when they can no longer care for them can cause great anxiety.

An Australian longitudinal study of families of children with autism (Gray 2002b) found that both the child's and the family's problems often worsened at adolescence with the onset of physical and sexual maturity (see also Schneider et al. 2006). There was an increased frequency of seizures among those with epilepsy, and parental emotional distress and exhaustion were common, especially for mothers. The absence of services appropriate for adolescents and adults with autism was pressing, especially the kinds of supports the children were going to need when their parents are no longer able to care for them (Gray 2002b).

A Swedish study (Billstedt & Gillberg 2005) prospectively investigated over a hundred people diagnosed as children in the 1960s, 1970s, and 1980s, for periods ranging from 13 to 22 years until they were aged from 17 to 40 years. The study found that they had worse psychosocial outcomes than had previously been believed. Overall, the outcome was poor in around 78 per cent of cases. Only four people were living independently and even they were leading fairly isolated lives. Impairments had become more severe in adolescence for almost 20 per cent, and this appeared to be permanent in about half these cases. Self-injury and extremely violent behaviour were common, although at the same time there were many parents who reported that their ASD child had had a fairly uneventful adolescence. Major medical problems were also common, even in people who had no underlying medical disorder. The researchers noted that these findings related to a population who had been diagnosed 13 to 22 years before, and hence could not be assumed to apply to children diagnosed more recently. They also noted that the findings might not be relevant to individuals in the upper ranges of the autism spectrum.

A UK study (Howlin et al. 2004), which followed up 68 individuals in adulthood (ages 21 to 48 years) first seen in childhood (ages 3 to 15 years), had similar findings. Although a small number were fairly independent as adults, most of them were still very dependent on their families or other support services. Few of them lived alone, and most had no close friends or permanent employment. Their communication abilities were generally impaired, their reading abilities poor, and they persisted with stereotyped behaviours. The authors acknowledged that education and therapy for people with autism had improved over the past three decades, but that many remained dependent nonetheless. They said that people with higher IQ ratings (>70) did do better than those with lower scores, but that the ability to function adequately in adult life depended as much on the support available as it did on intelligence. Unfortunately, services for adults with autism had not kept pace with services for children.

A Canadian study (Eaves & Ho 2008) found that the young adults who participated in the study had better outcomes than those who had participated in earlier studies (including the Billstedt and Gillberg study described above). The study used parent reports to investigate the progress of young adults who had been diagnosed when they were preschoolers. It found that, at an average age of 24 years, around half had outcomes that were good to fair, and while the outcomes for 46 per cent were poor, none had outcomes that could be rated as very poor. The researchers attributed the better outcomes in this study than in earlier studies, to the fact that young people now have more opportunities than previously, as a result of early identification, full inclusion in schools and better educational practices. Nonetheless, the young people still had unmet needs, particularly in relation to social life. Co-morbid conditions such as obesity and medication use were common; and the families reported that these young adults had limited independence and very little money or earning capacity, and that many had persisting behavioural problems.

A US study (Shattuck et al. 2007) investigated changes in autism symptoms and maladaptive behaviours over a period of four and a half years, in 241 children, adolescents and adults who were aged 10 to 52 years when the study began. Maladaptive behaviour was defined as behaviour that interfered with everyday activities, such as self-injury, withdrawal, uncooperativeness, aggression and destruction of property. The study found that, although the symptoms and behaviour of around half of the sample did not change over the course of the study, there were more people who improved than people who got worse—only a small proportion experienced increases in their symptoms and maladaptive behaviours. Moreover, the older people were (over 30 years), the less likely they were to engage in such behaviours. The researchers noted that these findings showed the importance of taking a life course perspective on change and development among people with ASD, rather than focusing disproportionately on very young children. People did tend to improve as they got older, but there is no evidence that these improvements are spontaneous. They could be due to the cumulative effects of interventions and medications. Moreover, most of the people in the study remained significantly impaired and dependent on others for help with day-to-day living. The researchers therefore recommended extending ASD interventions and services across the whole of the life course.

A study in Utah (Farley et al. 2009) examined the adult outcomes of 41 people with ASD (38 men and 3 women) with IQ ratings near-average to average ( $IQ \geq 70$ ), who had been originally identified through an epidemiological survey of ASD between 1984 and 1988. Only one person at the original assessment was over the age of 14 years, and ages ranged from 22.3 to 46.4 years at the time of the current study. Outcomes were found to be better than those for people with similar cognitive functioning in previous studies, with half the participants being rated 'good' or 'very good' on a global outcome measure. The authors advised caution in interpreting these findings, largely because of limitations in the sampling. But there was one factor that may have had a particularly telling influence on the results—38 of the 41 people (93 per cent) were members of the Church of Jesus Christ of Latter Day Saints (LDS). Not only is inclusion of people with disabilities a LDS cultural value, families are often large, community cohesion is strong, and children go to school, attend church and live in a neighbourhood as a cohort. Given that the sample was drawn from a unique geographic and cultural group with a significant religious influence, it may not be representative of other adults with ASD and average-range cognitive abilities (Farley et al. 2009).

A number of studies have documented the added stressors adolescence brings both for the children themselves and for their parents (largely their mothers). Not only are there problems related to adolescence itself—the child's increasing size and strength, approaching chronological adulthood without concomitant abilities for independent living—the system of formal services families relied on when the child was young, and sometimes the informal support as well, are coming to an end. This is also the time when some parents may be faced starkly with the likelihood that their son or daughter will never be an independent adult. This does not mean that nothing can be done or that no improvement is possible, simply that the need for services does not diminish as young people with ASD reach adulthood. The next section looks at some interventions with adolescents and young adults.

## 2.2 Interventions

Not surprisingly in the light of the situation described above, the literature on interventions for managing autism tends to be focused on early intervention and hence on young children. For example, Kadzin and Weisz (1998) do discuss treatments for adolescents (as well as children); but autism is only one of a number of problem domains they deal with, and their discussion in this context is largely confined to the program developed by Lovaas and colleagues, and hence (once again) to treatments for young children.

However, once again, there is work that has begun to fill the gap. In what follows, SST has been distinguished from behaviour modification. Although both forms of intervention are often found together, there are differences between them. SST involves introducing people with ASD to the skills necessary for interacting socially with other people, skills that the typically developing population acquire automatically but for which some people with ASD need special tutoring. Behaviour modification refers to interventions for decreasing the incidence of behaviours associated with ASD including fixedness. Interventions for extremely challenging behaviour by people with ASD have been shown to be effective in some instances, and pharmacological treatments are increasingly discussed.

### Social skills

Social skills training (SST) is an intervention developed specifically for teaching children particular social skills (for example, maintaining eye contact, initiating conversation) through behavioural techniques. These interventions are usually group-based as a way of providing opportunities for the children to practise their newly acquired skills in a relatively ordinary context where they are interacting with other children (Williams White, Keonig & Scahill 2007). Because ASD centrally involves difficulties with social interactions and relationships with other people, training in social skills has played an important part in treatment interventions (Barry et al. 2003; McConnell 2002). According to Herbrecht et al. (2009), the first published accounts of group-based social skills approaches designed specifically for ASD date from the 1980s, in the TEACCH program at the University of North Carolina. The Division of Teaching and Education of Autistic and Communication related handicapped Children (TEACCH) in the School of Medicine, Department of Psychiatry at the University of North Carolina Chapel Hill, is a statewide program for people with ASD and their families. It began as a research project funded by the US National Institute of Mental Health and the US Office of Education in 1966. It provides clinical services, conducts training and consultations nationally and internationally, and engages in research (<<http://teacch.com>>). Originally for young children, the program was expanded to include adolescents and young adults once it was realised that autism was a lifelong condition (Bristol & Schopler 1983).

A bi-national (US–Israeli) study of two-person friendships of pre-adolescent children (Bauminger et al. 2008) investigated three types of dyadic relationship between children to discover whether there was any difference in the social skills of autistic children depending on who they were relating to. The dyads were a child with high functioning autism (HFA) with a typically developing child ('mixed',  $n=26$ ); both children with ASD ('non-mixed',  $n=16$ ); and neither child with any category of ASD or disability ( $n=31$ ). The study found that the interactions in the 'mixed' friendships more closely resembled those in the friendships between the typically developing children than those in the 'non-mixed' dyads. The mixed friendships were more durable than the non-mixed ones, and showed higher levels of goal-oriented social behaviours, more responsiveness to each other, higher levels of positive social orientation and cohesion, and more complex play. This was despite the fact that the children with HFA in both mixed and non-mixed categories were more similar to each other than they were different. Moreover, many of the observational measures of the mixed dyads were more similar to the friendships of the typically developing children, than they were to the non-mixed dyads. These findings suggest that exposing children with ASD (at least those at the high end of the spectrum) to their age peers who are developing typically does have positive effects on their social abilities. The authors warn, however, that it is premature to draw any such conclusion drawn from this study, since there may also be negative aspects to 'mixed' groups, for example, power imbalances whereby the child with ASD has less opportunity to lead and initiate.

The findings of a German pilot study (Herbrecht et al. 2009) evaluating the effectiveness of an outpatient group-based intervention for improving social and communication skills has shown promising results. The intervention was the Frankfurt Social Skills Training program called KONTAKT, which was used to treat 17 children (aged 8 to 12 years) and adolescents (13 to 19 years) (15 male, 2 female, IQ  $\geq 70$ ) over a period of 11 months. KONTAKT is a program focused on such skills as making social overtures, engaging in conversation, understanding social rules and relationships, identifying and interpreting verbal and non-verbal social signals, problem solving and coping strategies, while at the same time improving the person's self-confidence. It was found to be useful for enhancing social skills and reducing autism-related psychopathology, both over time and in different contexts, although the researchers believed its usefulness would need to be confirmed through controlled trials (Herbrecht et al. 2009).

A review of the research literature on group-based SST programs for school-age children and adolescents (14 studies) (Williams White, Keonig & Scahill 2007) found that empirical support for this approach was incomplete, although the review did identify some promising intervention strategies. The authors noted that 'considerable progress' had been made on technique identification and the development of training manuals. They noted, too, that many of the studies demonstrated that youth with ASD can improve their social skills, although it was not clear that this improvement could be generalised to skills that were not directly taught or to the child's daily life apart from the training setting. 'Generalisation and flexible skill use in natural environments continues to be a challenge', they said (Williams White, Keonig & Scahill 2007, p. 1865). In their preliminary review of the research relevant to their pilot study, Herbrecht et al. (2009, p. 328) found only one report of a study where acquired skills were generalised to settings outside the training context. Williams White, Keonig & Scahill (2007) concluded that very little was known about efficacious psychosocial interventions and called for further and more systematic research.

A later review of 10 studies of SST programs for youth with AS and HFA (Rao, Beidel & Murray 2008) found that the empirical support for these programs was minimal, despite their widespread clinical use (see also Herbrecht et al. 2009). This did not mean that the programs were not beneficial—Rao, Beidel and Murray noted that their utility for other psychological disorders was well-documented. But the studies relating to the AS/HFA population were found to be inconclusive for a number of reasons, including the lack of a common definition of what constituted social skills; varying levels of treatment intensity and duration across the studies; disparate theoretical assumptions; and differences in the settings where the services were provided (for example, clinic, classroom). The authors made a number of recommendations based on their critical review: the tailoring of programs for ASD youth to match the specific social skills deficits, both of ASD in general and of particular subgroups within the category; the use of randomised controlled trials with samples large enough for statistical investigation; both short-term and long-term follow-up studies; generalising skills outside the treatment situation with unfamiliar peers and adults in unfamiliar settings; and the development of comprehensive, manualised social skills programs that could be easily implemented in naturalistic settings such as schools and community centres.

'Theory of Mind' (ToM) is a psychological theory based on the postulate that people make sense of others' behaviour and predict what they will do by attributing to others those mental states (thoughts, beliefs, desires, intentions, emotions, and so on) they themselves experience. Synonyms are 'mind-reading' or 'understanding other minds' (Baron-Cohen 2001). On this thesis, people with ASD can be said to suffer from problems with ToM. They lack or have a deficient 'ToM' that would enable them to make sense of what typically happens in relation to other people.

There is some evidence to suggest that this lack (or deficiency) depends on a prior lack, that is, of a self that experiences the states of mind behind the theory. The results of a UK study (Mitchell & O'Keefe 2008), for example, raised the possibility that people with ASD were not aware of having first-person privileged access to their inner states of mind. The study matched 24 young adults with ASD and AS (19 males and 5 females), with a non-clinical group of 24 young adults with typical development. Both groups were asked questions aimed at discovering whether individuals with ASD/AS assigned more knowledge to themselves about a situation than to a companion who shared the same situation, and whether or not they differed from the non-clinical

group in the relative assignment of knowledge. The ASD/AS participants did tend to assign a similar amount of knowledge to their companions as they assigned to themselves, in contrast to the non-clinical group, who assigned more knowledge to themselves. The authors commented that their study complemented other studies into the ways in which people with ASD conceptualised themselves (for example, Hobson et al. 2006), which have identified marked differences between people with ASD and those without, in the extent to which they understand themselves.

Another Utah study (Ozonoff & Miller 1995) was the first SST program to specifically target ToM abilities among people with ASD. It investigated the effectiveness of a four-and-a-half-month ToM training program with five adolescent boys with normal IQ ratings. Although the program was short term and the sample small, the study had a control group of autistic boys who did not receive the treatment, and it involved blind assessment. The results indicated that providing systematic instruction in ToM principles could improve performance substantially on several false belief tasks (that is, being able to predict someone's behaviour on the basis of what that other person believes to be the case, even though that other person's belief is false), although the researchers acknowledged that the improvement was confined to the one specific task and was not generalisable to other tasks. Nonetheless, they believed it was important to show that strategies for solving false belief tasks could be taught, because it meant that at least some aspects of ToM impairment could be helped by treatment (Ozonoff & Miller 1995).

Another researcher (Tager-Flusberg 2007) has pointed out that, although the ToM hypothesis is a valuable aspect of the treatment of ASD, no single hypothesis by itself can explain the full range of symptoms that define autism. ToM treatment is an adjunct to SST. It is, however, a new area of treatment for older children and needs more research.

### **Behaviour modification**

One aspect of ASD that causes difficulties both for people with ASD themselves and those in contact with them is challenging or very restricted behaviour, and many of the treatments for ASD are specifically designed to deal with this aspect. Research has found that families with children with intellectual disabilities rate behavioural problems as a greater source of stress than families with profoundly physically disabled children (Tonge & Einfeld 2003).

Behavioural problems in adolescents with ASD can manifest themselves in a variety of ways especially at school. These can range from inattention in the classroom, hyperactivity, defiance, anxiety or even depression (Ashburner, Ziviani & Rodger 2010). A Queensland study found that due to the behavioural problems more than 50 per cent of the children diagnosed with ASD, HFA or AS performed well below their academic potential despite having specialist support in the school (Ashburner, Ziviani & Rodger 2010). Challenging behaviours are often used by the adolescent to stop them having to participate in a particular activity, allay anxiety or self-stimulate (O'Reilly et al. 2010). A further problem with challenging behaviours is that before effective treatment can be provided the behaviours need to be analysed as to their role and the 'reward' they provide (O'Reilly et al. 2010). In addition, co-morbid impediments need to be identified such as social skills, communication skills and features such as anxiety or depression. O'Reilly et al. (2010) recommend a functional assessment be carried out with the child's carer to assess the role the particular behaviour takes. In a small study (n=10) students were offered alternative, more acceptable forms of communication to get their views across. By using simple techniques and offering verbal communication solutions, antisocial behaviour such as screaming or hand flapping was quickly replaced with alternative options.

There is some evidence that behaviour intervention is better than special education for children with ASD (Couper & Sampson 2003). Couper and Sampson (2003) cite a Scandinavian study where intensive behaviour therapy was measured against special education. The cohort of school-age children receiving intensive behavioural therapy improved on average 25 language IQ points. Skills were taught in small steps and then generalised. Parents played a major role in generalising the skills learnt. Though this study was on primary school-age children, it emphasises the importance of behaviour therapy, especially that which is intensive.

Cognitive Behaviour Therapy (CBT) has been shown in clinical tests to improve behavioural skills and social skills alike (Wood et al. 2009). By replacing bad behaviours with alternatives in the child's memory and allowing them to apply those behaviours in a variety of settings, the child is able to manage their anxiety, which is at the core of many behaviours within autism. In a small scale trial with 7 to 11 year olds, CBT appeared to improve reciprocal communication skills and this led to improvements in other autism associated symptoms (Wood et al. 2009).

Positive behaviour support in particular is a growing application that can be applied to school and home environments alike. Based on the fundamentals of Applied Behaviour Analysis (ABA), the program is preceded by a functional assessment that identifies the behaviours, when they occur and what potentially triggers them. The family and young person are then taught techniques to ameliorate the behaviour from positive time out to alternative strategies (McVilly 2002). McVilly (2002) argues the importance of behavioural intervention is that it can reduce the social isolation brought on by antisocial behaviour.

A US study (Van Bourgondien, Reichle & Schopler 2003) monitored the progress of a small group of adolescents and adults in a combined residential and vocational TEACCH training program over an 18-month period for improvements in behaviour. The average age of the participants at the beginning of the study was 25 years (ranged from 16 to 48 years). There were 32 people in the study, of whom six participated in the residential TEACCH program, while the others comprised three control groups: 10 living in group homes, six living in institutions and another 10 who were living in family homes. The participants in the TEACCH program did experience statistically significant improvements in a number of areas—communication, social skills, developmental planning, and positive, preventive behaviour management strategies—and significant reductions of behavioural problems, in comparison both with their own starting points and with the control groups. There was no improvement in developmental levels, but that was not to be expected given that these people would have been receiving training for a number of years already. The researchers concluded that, if the positive behavioural effects were to be maintained, programs such as TEACCH would need to be ongoing. They suggested thinking of such treatment strategies as 'prosthetic devices that help the individuals with autism compensate for their deficits (similar to glasses or hearing aids)' (Van Bourgondien, Reichle & Schopler 2003, p. 139).

A small US study showed that even adolescent boys with severe antisocial behaviour could learn to modify their behaviour in order to complete everyday tasks such as supermarket shopping (Carr & Carlson 1993). The improvement was maintained for between 25 and 35 follow-up sessions. The authors commented that one of the most important aspects of this intervention was its curbing of problem behaviour in public. Its success suggests that it may be able to enhance the quality of living for people whose opportunities for community involvement would otherwise be severely limited.

However, as in the case of SST, although there have been some promising developments in behaviour modification programs, the evidence is equivocal. While individual studies show hopeful results, there is little evidence that initial improvements continue in the long term.

### **Challenging behaviour**

Where present, challenging behaviours such as aggression and self-injury can be among the most impairing characteristics of ASD. Positive behaviour support and a functional approach to problem behaviours are recognised as best practice in treating ASD (Roberts & Prior 2006, p. 51). ABA methods include functional assessment, data collection and skill replacement. However, the focus of discrete trial training and, on early ABA programs, replacing undesirable behaviours with desirable ones, has been criticised as insufficiently attentive to family and social systems. Systems approaches emphasise the dynamics and interactions between members of a social system such as a family or school, rather than focusing on a single challenging behaviour. They draw attention to the multiple determinants of behaviour, including its meaning and function for the individual exhibiting it, and the environment in which it occurs (Evans, Meyer & Buckley 2008). One implication of this is that parenting styles, reactions and attributions are relevant to understanding the behaviour of the child with ASD and intervening to change it. This may be difficult for parents to understand or accept, especially if, as research has found, children's behaviour is mistakenly attributed by parents to autism and therefore understood to be internal to the child (rather than caused by a situation or environment) and unchangeable (Whittingham

et al. 2009b). A further implication of a systems approach is that instructing parents in broad, general principles of positive parenting techniques will be more effective than expecting them to apply specific ASD intervention techniques. Stepping Stones Triple P are robust generalist positive parenting programs with emergent evidence of effectiveness for parents of children with ASD (Whittingham et al. 2009a, 2009b, 2009c). Signposts for Building Better Behaviour is an education and support program for parents of children with intellectual disabilities. It was implemented across Victoria in 2005 (funded by the Department of Families, Housing, Community Services and Indigenous Affairs and the Victorian Department of Human Services). Evaluation of this wide-scale implementation found statistically significant improvements to parent and child outcomes (Hudson, Cameron & Matthews 2008).

Adolescents and adults with severe challenging behaviours require intensive specialist support services. For example, a positive behavioural support intervention was implemented in Ireland for five people (including two with autism and co-morbidities) whose behaviour was rated on a severity scale and defined as behaviours that 'caused very serious tissue damage to other person/self (bones broken, deep lacerations/wounds)' (McClellan, Grey & McCracken 2007, p. 284). The evaluation of the intervention showed substantial reductions in challenging behaviours and a reduction in total revenue costs of services for the five individuals, although this was skewed by the significant savings of costs to one individual and the costs of services to the others increased. It concluded that people with severe challenging behaviours can maintain their place in the community provided that they are supported by a comprehensive range of tertiary services, including acute short-stay psychiatric treatment in mainstream psychiatric hospitals; small (one or two bed) community respite facilities adapted for challenging behaviour; individualised residential and day services; high-support homes in the community; and on-call intensive support service (McClellan, Grey & McCracken 2007). Separate prevalence studies from the UK suggest that around 4.5 per 10,000 population, or about 10 per cent of the total learning disabilities (Lowe et al. 2007) and intellectual disabilities (Emerson et al. 2001) populations have severe challenging behaviours, and substantial numbers of others have challenging behaviour at lower degrees of severity. It is therefore likely that numerically few adolescents and adults with ASD will exhibit severely challenging behaviour, but those that do require intensive tertiary support services of the kind described above. More people with ASD will be less severely challenging, and require specialist secondary support services.

There is an enormous literature on ASD, and a similarly large literature on challenging behaviour, mostly separate from that on ASD. It was not possible within the constraints of this project to conduct a systematic review of this literature, and relatively few families affected by a diagnosis of ASD will require the support services necessary for managing severe or moderate challenging behaviour. Those families who do require these services may initially make contact with ASD services or websites, so it is important that these services can make referrals where necessary.

### **Pharmacological treatment**

Behavioural interventions are indicated for younger children, or when symptoms occur only in certain environments. If behavioural interventions have been unsuccessful, if symptoms are persistent, or if co-morbidities such as depression are present with ASD, pharmacological treatments are increasingly used (Hollander, Phillips & Yeh 2003). None are specifically designed for ASD but have been borrowed from other disorders to target particular conditions or behaviours. Typically drugs are prescribed to treat aggression, anxiety, hyperactivity and stereotypic or repetitive behaviours. The safety and efficacy of these drugs for children and young people with ASD, and their side effects, is of clinical and parental concern. The children in our study on medication were prescribed fluoxetine, a selective serotonin reuptake inhibitor (SSRI), and risperidone, an antipsychotic. Antipsychotics are the only specified medication on the Raising Children Network's 'Helping Children with Autism (HCWA)' web page.

Fluoxetine (trade name Prozac) is an SSRI that has been shown to be effective in some trials with ASD populations, although these studies suggest that 'core' ASD symptoms are less responsive to the drug than symptoms that overlap with mood disorders (such as depression) and obsessive compulsive disorders. Risperidone is an atypical antipsychotic prescribed to children with ASD to treat aggression. Its documented



side effects included nervousness, weight gain and increased appetite. A Cochrane (Jesner, Aref-Adib & Coren 2007) review of risperidone for ASD found that it may be of benefit for behavioural problems, although a small number of studies were eligible for inclusion in the review and the authors urge caution in interpreting findings, especially around the effects of long-term use of the drug. Meta-analysis suggested significant improvements in irritability, withdrawal, hyperactivity and stereotypical behaviours. The most common adverse event was weight gain, most notably in children aged 5 to 17 years.

### **Summary**

There is an enormous, and fast-growing, literature on the natural history of ASD, changes in symptoms over the life course, and lessons for clinicians (especially psychiatrists and psychologists) and educators. However, this literature gives no definitive answer to the best approach for older children and adults with ASD, as symptoms are so diverse within ASD, and the 'fit' for children and families of treatment modalities is so important. Information on single interventions are less useful to families than information on the range and nature of services available to them, and information that addresses the immediate needs of their children, especially challenging behaviour, social distress or isolation. There is a strong message within the literature for large-scale controlled studies of a range of interventions, which will be useful for families in the long term. Families who are looking for information on available services, however, are unlikely to find the clinical literature useful unless they have quite a high level of research literacy. Moreover, one of the more promising interventions with older children is TEACCH, which is not currently available in Australia. The first steps for assisting parents of older children with ASD would seem to be making available information on treatments commonly used with older children, including pharmacological treatments, on the Raising Children Network website.

## **2.3 Transition planning**

Transition planning involves interventions specifically directed towards adolescents and young adults. The transition from adolescence to adulthood is a stressful time for anyone, but particularly so for young people with disabilities (Hughes 2001). Because their options tend to be limited, they require more support than most. This is also a time when young people can get lost between children's and adults' services, finding their support cut off from one day to the next at their 18th birthday, and thrown back on their own unaided resources and those of their families (McGrath & Yeowart 2009).

For young people with disabilities, the process of acquiring the rights, responsibilities and privileges of adult life is normally prolonged into the ages when, for most people, adult life is taken for granted. For that reason, transition planning needs to be comprehensive and address all major areas of adult life: continuing education, employment, daily living, health, leisure, self-determination, residence and community participation. However, most of the transition literature focuses on employment, although there is evidence to suggest that the single factor that best predicts a student with disability's future capacity for paid employment is the ability to manage activities of daily living (Eagar et al. 2006).

One aspect of daily living that receives little attention is transport. Inadequate access to transport can be the result of parents' concerns about their young person's safety. But restricting their ability to get around by themselves can have a significant detrimental effect on a young person's opportunities for leisure, employment, and making and sustaining friendships (Dyke, Leonard & Bourke 2008).

According to a UK guide for funders and charities supporting young people with disabilities (McGrath & Yeowart 2009), 'transition' refers to the period from 14 to 25 years, when significant changes are occurring in young people's lives and decisions have to be made about the future. Although major changes do not usually occur before the age of 16 years, it is advisable to start transition planning before that age. Other researchers have advised starting even earlier, between 10 and 13 years of age (Hendricks & Wehman 2009). The main types of transition for adolescents and young people are from school to further education; from living at home (or residential school) to living somewhere else; from education to employment; and from children's services to services for adults.

People with ASD have particular difficulties with change—this is one of the diagnostic criteria of the disorder—and hence they need support to help them with what can be a terrifying experience (McGrath & Yeowart 2009).

Transition programs are increasingly being influenced by the concept of self-determination, which has emerged in recent years within the disability policy literature and research both in Australia and elsewhere. Self-determination in this context is defined in terms of skills such as goal-setting, decision making, problem solving, communication, self-awareness and self-advocacy (Laragy 2004). However, a recent Australian summary of evidence relating to the transition of youth with intellectual disabilities (Dyke, Leonard & Bourke 2008) noted that the ideal of self-determination for intellectually disabled youth was far from being achieved. In the first place, transition services seldom took account of the things young people themselves thought were important, such as friendships, social life and leisure. As well, when people had limited speech ability, assumptions and services were often imposed on them. Although Transition Support Models have been developed and strategies suggested for implementing these models, to date there had been little attempt to find out whether such models had had any impact on the young adult's subsequent wellbeing and participation in adult life. Moreover, the leisure activities proposed typically involved a narrow range of stereotypical activities, such as arts and crafts or bowling, and they usually occurred in segregated settings or only with other individuals with disabilities. The authors concluded that, although many initiatives had been implemented across the developed countries for facilitating transitions from secondary school, not many had been able to sustain what is needed to ensure that young disabled people could participate in adult life as well as they were able.

Two decades ago (in 1989), the NSW Department of School Education (now the NSW Department of Education and Training, DET) funded a pilot transition program to help students with disabilities as they moved from school to the community (Parmenter 1999; Riches 1996). The program recognised that a number of different transition outcomes had to be addressed, not just employment, as young people moved from school to adulthood, including financial security, housing arrangements, living in the community, recreation, friendships and quality of life generally. Evaluations identified the transition program as a model of best practice, but researchers noted six years after the initiative began that the gains depended on departmental support and budgetary considerations, and that these were subject to change.

The importance of transition planning and support for adolescents and young people with disabilities is recognised in the DET's most recent Disability Action Plan (DET 2004) although the focus is solely on training, employment and further education. DET 'aims to provide students with a smooth transition from school to school, from school to work or further study, and from post-compulsory education and training to work or further study' (DET 2004, p. 5). To achieve this aim, DET has appointed Teacher Consultants, both in schools and TAFE, whose role is to facilitate the participation of students with disabilities, including their transition to employment or other education programs. DET has also appointed itinerant support teachers (autism is specifically mentioned in this context), and provided for the development of staff awareness and understanding of vocational learning, with particular reference to the career and transition needs of school students with disabilities.

There have been significant policy developments recently in the UK in relation to transition planning for adolescents and young adults with disabilities (Dyke, Leonard & Bourke 2008). The UK *Education Act 1996* had already mandated a Special Educational Needs (SEN) Code of Practice for all state schools and early education settings, as well as local authorities and health and social services. The term 'special educational needs' means learning difficulties or disabilities that make it harder for these children to learn than others of the same age. The law states that all children with SEN should have their needs met, preferably in mainstream schools, that the views and wishes both of the children and of their families should be taken into account, and that the children should get a broad, well-balanced and relevant education. Assessments of children's educational needs, based on specialist advice, are made by the Local Education Authority (LEA), and if a child needs special help, the LEA must write a statement of special educational needs—usually called 'a statement'. This describes and lists the child's needs, along with the special help he or she is to receive (UK Department of Children Schools and Families 2009). Young people with learning difficulties and disabilities are assessed in the last year of compulsory schooling, in Year 11, and at the point of leaving school and up to the age of 25 years (UK Government 2007).

In 2007, the UK Government launched a transformation program for services for disabled children in England. Called 'Aiming High for Disabled Children' (UK Government 2007) it was the culmination of the UK Government's Disabled Children Review, and identified services for disabled young people in transition to adult life as one of the major areas where improvement was needed. An important aspect of the transformation program was, therefore, a Transition Support Programme (TSP) for disabled young people moving into adult life (UK Government 2007, p. 7). It currently consists of two main elements: a national transition support team, comprising the Council for Disabled Children and partners, to coordinate the work in conjunction with local authorities, primary care trusts (responsible for primary health and community services at the local level), regional advisers and existing experts; and a combination of direct grants and regional adviser activity as a way of supporting change at local level.<sup>2</sup> There are five principles underlying the TSP: comprehensive multi-agency engagement; the full participation of young people and their families; the provision of high quality information; effective transition planning; and an array of opportunities for living life (Merriman 2009).

The UK charity, MacIntyre, has a transition-from-school program for young people with learning disabilities. Called 'My Way', it was set up to improve support for the young people graduating from the two specialist residential schools it runs. A facilitator starts working with the young person two years before they are due to leave school, helping them to think about their options for living arrangements, about what they want to do, and about how they want to be supported. The facilitator also coordinates regular meetings between people involved with the young person's transition, including professionals such as teachers and social workers, as well as family and friends. The facilitator organises the individual budget (if it is available), or alternatively negotiates with the local authority to arrange funding support on the young person's behalf. The approach is 'person-centred'. It requires ongoing consultation with the person involved, so that the planning takes into account what is important to the person for whom the planning is being done. It also actively takes into account and consults the people who are close to the young person making the transition (McGrath & Yeowart 2009).

The UK National Autism Society (NAS) All-Party Parliamentary Group on Autism (APPGA) (Allard 2009) selected transition to adulthood as a topic for inquiry because, although some areas had seen much progress, the transition process itself and the links between services often failed people on the ground. The author of the report on the inquiry pointed out that only 15 per cent of adults with autism were in full-time paid employment, and that only 53 per cent of young people with ASD who had SEN statements had been issued with transition plans during their education. This fell to just 34 per cent of students in mainstream schools. She also pointed out that, although this was a failure of the system, it was too often seen as a failure of the young people themselves, with sometimes catastrophic consequences. Submissions to the inquiry highlighted a number of factors that were central to effective transition: planning that was effective and timely, and that was realistic yet also stretched expectations; effective working across services; understanding of ASD among professionals; accessible information for young people and their families; and appropriate funding. But, the report concluded, for many people with ASD transition is not working, either in the narrow sense of a smooth handover between child and adult services, or in the sense that those with autism are being provided with the support they need in order to lead fulfilled adult lives. The report welcomed the TSP, but noted that the best of transition processes are useless, if the fundamental problem is that there is nothing to transition to.

This section summarises the recommendations for changes to service delivery and support, as described by our interview participants and implied by the literature review.

### **Behaviour support**

- Just as with early intervention there needs to be support for adolescents with ASD. Support needs to be targeted at both those who were diagnosed in early childhood and those who have only recently been diagnosed with ASD, and should include behaviour and social interventions according to their needs. An assessment of their requirements would incorporate the family, school and the adolescents' needs as well.
- For a small minority access to emergency care is required. This would probably revolve around the mental health team and would include follow-up strategies including behaviour support within the home.

Emergency support needs to be available 24 hours a day, providing a mixture of telephone support through to harm intervention teams, who can provide alternate accommodation when the adolescent is at risk of harming themselves or others.

- ▶ Intensive multidisciplinary behaviour intervention programs are highly valued by those who have experienced them. These include the programs offered by Redbank School in Westmead, New South Wales, and the Learning Differences Centre at the Royal Children's Hospital, Melbourne.
- ▶ Behaviour Intervention Teams such as those provided by the Department of Human Services in Victoria are able to work with the family in their home. Support initially needs to be frequent and consistent.
- ▶ For some families, ready access to a full support team of behavioural therapists, psychologists and social workers may be required for the period, particularly during puberty when new difficulties sometimes arise.
- ▶ Families with complex needs require case management services. Case managers would put families in touch with appropriate services and provide ongoing support.

### **Life skills**

- ▶ Life skills training, such as that run at TAFE, should be offered to students from junior high school and extend to job training opportunities.
- ▶ Supported business enterprises need to be gender, age and skill appropriate to be attractive to people with ASD and their families. The presence of supported employment services in an area does not guarantee it will be useful to families, and in any case these services appear to be few in number.

### **Social skills**

- ▶ In general there appear to be social skills courses run in most cities. However, in several instances they are one-off and time limited. Social skills need to be reinforced on a regular basis to create competence and confidence.
- ▶ A wide range of social skills workshops, including those involving neurotypical peers and those that offer the opportunity to 'graduate' into social clubs, are likely to be successful. Programs must be attractive for adolescents as they are likely to refuse to go if not. Examples of this are the use of drama in the Social Skills program run by Autism Spectrum Australia (Aspect) New South Wales.
- ▶ Support needs to be provided for other social clubs and community activities, such as scouts and drama clubs, which provide a safe environment for adolescents with ASD to practice their social skills and acquire new friendships. Additionally, access needs to be provided to vacation courses that are residential to provide intensive social skill training. Vacation classes could include adventure courses that improve confidence. These clubs use the activities of music, film creation and running a newspaper to teach social skills. The clubs are staffed by staff with ASD experience but are essentially run by the adolescents.

### **Access to timely and authoritative information**

- ▶ Access needs to be provided to information similar to that on the Raising Children Network, which is aimed specifically at adolescents aged 11 years and over. This would include a list of available services in each area for adolescents including late diagnosis and funding availability.
- ▶ Drug therapies, especially SSRIs for anxiety and antipsychotics for behaviour, appear to be more commonly considered and used than most Australian ASD information sources would indicate. Information on benefits, contraindications and possible side effects should be available at popular ASD information sites, including the Raising Children Network's 'Helping Children with Autism' web page.

### Funding

- ▶ A comprehensive list of funding availability and the criteria for accessing that funding, both at federal and state levels, is required. Information should be made available through schools as well as through websites such as the Raising Children Network website.
- ▶ A development of an ongoing package of therapy availability similar to the Australian Government early intervention program, to provide financial support for ongoing therapy and psychology for adolescents, is needed.

### Integrated education and support environments

- ▶ There appears to be a need to create an environment where teachers, family and therapists cooperate and communicate to apply a level of consistency of approach across all areas of the adolescent's life. One example of this, described by one parent, is the not-for-profit Joseph Varga school in Sydney for children with learning disabilities, conduct disorders and/or emotional disturbances.

### Respite

- ▶ This research showed there were only a few families requiring respite. These tended to be single parents, or cases where there were severe behavioural problems. Respite needs to range from a few hours a week through to extended respite over weekends for more intensive cases.
- ▶ Vacation-based respite that combines social skills training with adolescent-appropriate activities was highly valued by those parents who had experience of it.

The results of a UK study indicated that special support can have a positive impact on the employment prospects of people with ASD. The study examined the outcomes for adults with ASD or AS (IQs  $\geq 60$ ), of a supported employment service run by the NAS, called 'Prospects'. Through work preparation, job-finding and support in the workplace, the service had enabled around 68 per cent of clients to find employment over an eight-year period (1995–2003). This amounted to 192 jobs in administrative, technical or computing work, most of which were permanent. The program did run at a financial loss, but there were many non-financial benefits, including improvements to people's quality of life and mental and physical health, reduced demands on families, and high satisfaction on the part of all concerned—clients, employers and support workers—and these are difficult to quantify.

Researchers have noted that, to the extent that the notion of 'transition' remains restricted to employment and independent living, it does not adequately address the needs of young people with severe disabilities because most of them remain living in the family home (McIntyre et al. 2004; Renty & Roeyers 2006) and few are in paid employment. It has been suggested that, instead of confining the goals of transition planning to employment and independent living, it would be more appropriate to devise ways of ensuring and measuring family coping and wellbeing (Schneider et al. 2006). A US study, which asked 30 mothers of young adults aged 18 to 24 years with severe intellectual disability about their children's quality of life, found that very few of them identified paid work as a factor. The largest category of responses related to getting their child's needs met, followed by having a social network and being happy. The researchers concluded that, to the extent that quality of life was the criterion for evaluating the success of transition programs for young adults with severe intellectual disabilities, those programs needed to be linked directly to the individual and their particular circumstances (McIntyre et al. 2004).

## 2.4 What families find effective

The Canadian study described above (Eaves & Ho 2008) found that, when people were asked directly what had been most helpful, they were more likely to mention people than treatments or services, although some of the people mentioned were service providers. Parents of people with ASD ( $n=48$ ) were asked in a phone interview: 'What three things have been the most important, helpful or made the most difference in raising your child over the years?' (Table 1). Family members, usually husband or grandparents, were the resource most frequently

mentioned (by 52 per cent of the parents), closely followed by other particular individuals such as a teacher or aide (50 per cent), although only a few people (7, 15 per cent) said the school was helpful. Some people named themselves (17 per cent). Agencies for people with disabilities (25 per cent) or offering specific autism support (16 per cent) were also mentioned. The authors commented that only one person said they found a particular treatment method helpful, although three people mentioned services their young adult had received before the age of 5 years. No one named behavioural therapy as such, but 16 per cent named agencies that offered it.

The authors commented: 'Not surprisingly, when families recalled what was helpful or not in raising their children, it was people, not a treatment method or program. Family members or individuals working closely with them were what they remembered as making a difference to them' (Eaves & Ho 2008, p. 746).

**Table 1: Supports and services found to be helpful or unhelpful**

Source	Helpful (%)	Unhelpful (%)
Family members	52	–
Individuals (teacher, social worker)	50	29
Association or agency	25	–
Self	17	–
Autism agencies	17	2
Lack of services/work	–	29
School	15	29
Ignorance/attitudes	–	27
Government departments	10	27
Nature of autism	–	15
Other professionals (doctor, psychiatrist)	8	12

Note: '–' = not applicable.

Source: Eaves & Ho 2008, p. 744.

Australian researchers Keen and Knox (2004) pointed out that there are times when interventions need to focus on the family as a whole, rather than simply on the individual with challenging behaviour, because of the critical role families play in the children's lives. They said that the shift towards a focus on maintaining family integrity had been incorporated into much government policy both within Australia (in the CSTDA) and overseas. They argued that this family focus should include understanding the family's lived experiences and their meanings and stories, and allowing that family members are the experts in their own experiences. Services should work with families in ways that enhance their sense of control over their lives. This would raise methodological difficulties for empirically validating the efficacy of an intervention. But one way to address this issue could be to work with the family to help them identify their own measures. A process like this would also avoid one of the problems with conventional data collection methods, that is, intrusion on family privacy.

In their own study with a single family (a lone mother and her three daughters with ASD), the researchers used intervention strategies where the family members themselves were the primary decision makers, and where the researchers were facilitators rather than playing a directive role. The researchers spent time with each member of the family singly, and with the family as a whole, to help them to identify problems and ways to solve them, while taking into account the family dynamics. In this way, the family played an active part in identifying the issues, devising the strategies, and working out ways these would be incorporated into the family lifestyle. From reports of the family members themselves, it was clear that the situation had improved as a result of the intervention; for example, school attendance was better, aggression within the family decreased, the children carried out self-care tasks when they were asked to. The authors acknowledged that there were many issues involved in family-centred practice that their study did not deal with. But, they said, the study did show that such an approach could improve the quality of life of a whole family, not just an individual (Keen & Knox 2004).

Another Australian study (Schneider et al. 2006) investigated the challenges faced by 20 families caring for adolescents with disabilities (aged 10 to 21 years), of whom four had a primary diagnosis of autism and four had autism as a secondary diagnosis, and the strategies the families adopted to sustain meaningful family routines during the adolescent years. The study found both internal challenges (for example, changing family roles and relationships) and external ones (for example, service discontinuity when the child reaches 18 years of age), and that families use multiple strategies to deal with these challenges. The authors concluded that professionals needed to be aware that families are not static across the life course, and that adolescence is a period that brings its own particular set of problems and issues. People working with families caring for adolescents need to gain an understanding of the dynamics of the family routine, and an appreciation of the demands placed on families by the unreliability of the system of services. Service providers can also learn from the coping strategies of families.

## 2.5 Service provision

Over a quarter of a century ago, US researchers listed services needed by autistic adolescents and young adults, including:

- educational and vocational training—primarily for helping adolescents reach their full potential, improving their social skills and helping the family by providing regular brief periods of respite
- parent training—in managing problem behaviours and as a way of providing continuity in the adolescent’s skill development
- medical and dental care—finding practitioners who can deal with young people with ASD
- respite care—in order to avoid family crises and as a way of enabling young people with ASD to continue to live in the community
- parent groups—for exchanging information and advice, for mutual recognition and valuing of their efforts on behalf of their children, and advocacy and political action
- support for independent living arrangements—because parents have a right to expect that their children will eventually be able to live apart from them (Bristol & Schopler 1983).

The authors found that many of the problems attributed to adolescence were in fact due to a lack of services, both for the child and support services for the family. The characteristics of the children of mothers suffering from high levels of stress were not fixed but were amenable to intervention. Moreover, a major difference between high and low-stress mothers was their level of satisfaction with their employment status, whether or not they were in paid employment. The difference was not between those women who worked outside the home and those who did not. Rather, the difference depended on whether or not they had some choice about that decision; and that choice usually depended on the availability of adequate child care (Bristol & Schopler 1983).

A Belgian study (Renty & Roeyers 2006) found that variations in the quality of life of high functioning adults with ASD were strongly associated with the degree to which their needs for formal support were met. Among those needs were accommodation, interpersonal relationships, daytime activities and ASD-specific information. The study found no association between quality of life and IQ level or autism-specific traits, although the researchers believed that further research would be needed to strengthen these findings.

A discussion by Victorian researchers in relation to service delivery for Australians with intellectual disabilities (Bigby & Ozanne 2001) argued that policy changes in the last decades of the 20th century did not necessarily improve life for people with disability and their families. While deinstitutionalisation and the implementation of supported community living had resulted in better care and physical surroundings, they had not led to greater social acceptance of people with intellectual disabilities. The authors also pointed out that the process of ‘dedifferentiation’, with more emphasis on generalist disability services, rather than special arrangements according to each disability group’s particular needs. While this would mean less emphasis on distinguishing

disability groups from each other, and hence could remove the stigma of specialist services, it could also lead to neglect, to loss of expertise and to diminished commitment to meeting those needs each group has that are not common across the whole field of disability. 'Equity for people with intellectual disability', the authors said, 'will not be obtained by invisibility' (Bigby & Ozanne 2001, p. 185).

The Australian study of 20 families by Schneider et al. (2006) found that, because there was very little informal support from outside the family, families were heavily reliant on formal services. But formal services were inadequate and sometimes non-existent. This was especially the case during adolescence and young adulthood, as the young people grew out of the age-range of services for children. Families found that they were forced into new rounds of bargaining for funds and had to search anew for services that they had formerly relied on. They also faced waiting lists and long delays, sometimes of years, and when services did become available families frequently found that they were no longer appropriate. Too often, it was impossible to plan because of the sporadic and short-term nature of funding and services, often the result of budget cuts when programs were changed or cancelled without notice or explanation. The researchers found that families devised three main strategies to deal with these difficulties: they actively and sometimes forcibly agitated for their rights and the rights of their disabled children, they took on the role of case worker and coordinated multiple services, and they did without. In the latter case, the consequent sacrifices could be overwhelming for family life, for example, someone giving up paid work to care for the young person, or the young person moving into a group home. While not all these factors are confined to adolescence, families do face additional difficulties at this time, and the discontinuity of service provision exacerbates those difficulties.

A Sydney study (Knox 2000) of 68 families with children with intellectual disabilities investigated the question of what kinds of interactions with service providers these families felt were consistent with family-empowerment principles. All 83 participants (all the mothers plus some of the fathers and one grandmother) agreed that having control was an essential aspect of the quality of their life as a family. Having control meant being offered support that strengthened and sustained them as a family, making their own decisions and not being pressured, and working in genuine partnership with service providers where their expertise was acknowledged, valued and used.

In a recent NSW report (NSWCCYP 2009) it was proposed that a more holistic approach to child development be created that includes sport and recreational activities and after school activities, which is inclusive of young people with disabilities to improve their self-esteem and social networking skills.

## 2.6 Siblings

Research indicates that the siblings of children with disabilities are at greater risk of adjustment difficulties, emotional symptoms and problems with peers than children without disabled siblings. They are also more likely to report depression and anxiety and to engage in problem behaviours. Moreover, longitudinal research has shown that such problems can persist over time and into adulthood. Given the body of evidence, it is clear that there is a need for effective support and intervention services specifically for siblings (Giallo & Gavidia-Payne 2008).

In a Queensland study of 25 siblings of children and adolescents with ASD (siblings aged between 8 and 15 years) (Ross & Cuskelly 2006), the mothers of 40 per cent of the siblings reported that the children had significant adjustment problems, predominantly internalising difficulties. Eighty-four per cent reported that their autistic sibling's aggression was their major concern. The researchers commented that aggressive behaviour may well be characteristic of sibling relationships in general, but the study did find that siblings of children with ASD were at increased risk of internalising behaviour problems (Ross & Cuskelly 2006). TEACCH researchers (Bristol & Schopler 1983) had found from their clinical experience, as well as from what they had learned from the research literature, that siblings could become self-conscious as they entered adolescence, and as they grew older they could start worrying about the possibility of having a disabled child.



A six-week intervention in Victoria for 21 siblings (aged 8 to 16 years) of children with disabilities or chronic illnesses and their parents (Giallo & Gavidia-Payne 2008) had some promising results, despite the short timeframe. Called *Sibstars*, the intervention was psychoeducational and based on cognitive behavioural principles. It was family-based, that is, it included the parents as well as the siblings. The program resulted in a decrease in the siblings' emotional symptoms, a reduction in the intensity of their feelings of stress in relation to their siblings (even though there was no decrease in the frequency of stressful incidents), and less use of avoidance as a way of coping. Family time and routines were strengthened, and there was a high level of parental satisfaction with the program.

Research has also found that siblings can be very supportive, both of their autistic brothers and sisters, and of their parents. TEACCH researchers noted that siblings were sometimes the only people, besides their parents and the teacher, who could manage their autistic brother or sister. Some parents reported that siblings became more sympathetic and helpful than before once they had left home, and particularly after they had had their own families (Bristol & Schopler 1983). A UK study of mothers of adolescents with intellectual disabilities (Todd & Jones 2005) found that siblings provided a flexible and trustworthy form of support that enabled the mothers to remain in paid work and maintain a social life, activities that were difficult if not impossible to sustain relying only on formal support services. The Australian study by Schneider et al. (2006) found that parents became more sensitive towards their non-disabled children as the children grew older and their needs changed. As the children became more independent, parents were more likely to allow them to engage in activities outside the home. At the same time, the parents in the study also said that there was a growing interdependence between themselves and their non-disabled children, as the children became capable of taking on part of the family workload, including aspects of the caring role. The researchers commented that the need to balance this interdependence with the children's independence was an important family dynamic to emerge as the disabled child entered adolescence.

The Schneider et al. study (2006) also found that the disabled children's relationships with their siblings changed as they entered adolescence. In many of the families, a gap opened up between the adolescent and their non-disabled sibling, as the latter developed interests outside the home and the disparity in cognitive abilities became more apparent. Older siblings sought to make their own lives—moving out, finding work, getting married—while younger siblings began to assert their own needs and to choose activities with their peers rather than their family. Siblings also became more conscious of their sister or brother as different. Some reacted to this with avoidance, embarrassment or even aggression, while others became more understanding and protective.

Siblings Australia is a national organisation devoted to enhancing the wellbeing of the siblings of people with special needs, including disabilities, chronic illness and mental illness (<<http://www.siblingsaustralia.org.au>>). It runs workshops designed to enhance the self-esteem of siblings of children with a disability and provides chat rooms for under 12 year olds and teenagers where siblings can talk about their feelings and problems of being a sibling of a child with a disability.



## 3 Methodology

### Analysis of data from the main study

We re-analysed data from the main study to address the research questions of this study. Of the 32 parents interviewed for the main study, two had children older than 8 years at time of interview so were included in this study. In addition, we drew on data from the 'school', 'post-school' and 'time' codes from the main study.

### Primary data collection

We interviewed parents and service providers about older children's and adolescents' experience of ASD, including therapeutic and educational services, transitions from school, employment and social participation.

Parents of children with ASD aged between 11 and 18 years of age were recruited via flyers in newsletters of support agencies, invitations via email of parents who agreed to be approached for research purposes and through websites and chat rooms (Autism Victoria; Nepean, Cumberland, Blacktown & The Hills Service Network Project). Flyers were also sent to autism support agencies in Queensland, New South Wales and Victoria.

Service providers were directly recruited by letter and included speech therapists, psychologists, early intervention service providers and a generalist early education and care centre that enrolls children with ASD. Diagnosing clinicians were recruited from Victoria, New South Wales and Western Australia.

Two parents were also service providers; one in NSW, one in Victoria. In the main study parents/service providers were in formal positions as service providers and had children much older than most of the others in the sample, so were interviewed primarily in their capacity as service provider. In contrast, the parents and service providers here are parents who have set up support groups and services.

The project had ethics approval from the University of New South Wales (UNSW) and state health human resource ethics committees (HRECs), and the ethics committees of SDN Children's Services and Autism Spectrum Australia (the national ASD peak body).

Interviews were transcribed verbatim and checked against the audio recordings. Identifying information was removed and aliases applied to all interviews. Transcripts were analysed using NVivo qualitative software, using open and axial coding, based on the research questions and emergent themes. Analysis involved the ongoing development and revision of codes to capture the themes as the process of analysing the interviews proceeded. Three researchers coded the interviews, commencing by double coding, and then when coding became consistent between researchers, by single coding and intermittent checking to ensure that coding remained consistent. Quotes illustrative of the themes emerging in these data are presented.

A total of 18 interviews were conducted between November 2009 and February 2010. Parents were from New South Wales and Victoria, and service providers from New South Wales, Victoria and South Australia. All the parents were mothers and, of the total of thirteen, eight lived in New South Wales and five in Victoria. Interview participants are summarised in Table 2.

**Table 2: Participant category, by state**

	NSW	Vic.	SA	Total
Mother	8	5	0	13
Service provider and parent	1	1	0	2
Service provider	1	1	1	3
<b>Total</b>	<b>10</b>	<b>7</b>	<b>1</b>	<b>18</b>

Most of the adolescents were in the range of 12 to 17 years with three families having more than one child with ASD. All the parents interviewed were mothers except one who was the grandmother and the legal guardian of her grandchild.

**Table 3: Current age of child with ASD, by state**

	NSW	Vic.	Total
12–14 years	2	2	4
15–17 years	5	2	7
More than one child in family with ASD	1	2	3
<b>Total</b>	<b>8</b>	<b>6</b>	<b>14</b>

Of the families interviewed, in four the child was under 15 years and currently in school. Two were not able to attend a full week of school due to anxiety. Of the seven older children, two were no longer attending school but attending TAFE and one was combining school with TAFE. Two were attending special school and two had been home schooled.

**Table 4: Time since diagnosis,<sup>(a)</sup> by state**

	NSW	Vic.	Total
<1 year	1	0	1
1–2 years	1	1	2
3–5 years	1	0	1
6–8 years	2	2	4
>9 years	2	1	3
<b>Total</b>	<b>7</b>	<b>4</b>	<b>11</b>

(a) Families with one child with ASD only.

Of those families where there was more than one child with ASD: in two families there was more than nine years since diagnosis of both children in the family (in one case twins); and in the other family one between 3 to 5 years and one between 1 to 2 years.

### *Limitations of the study*

The limitations of the main study also apply to this one.

This is a qualitative study and the sample is not statistically representative of the Australian population. Parents volunteered to participate and were recruited indirectly and via websites and support organisations, in accordance with the protocols of ethical research. We therefore spoke to parents who were connected with networks of service and support, and cannot generalise these findings to parents who do not know about or do not use these networks. A number of the parents were extremely active in supporting other parents and advocating for improved service provision, and are probably atypical in their efforts. We did not interview children with ASD or their siblings, and their perspectives are not included here. We recognise that this is a significant limitation of any research on the experience of families with a child with disability.

## 4 Findings

This section reports on the results of interview data analysis, which are organised according to the research questions and themes emerging from the data.

Our study sample was quite small (although valid for a study of this type), but within this sample a lot of variation in needs, strengths and approaches to intervention was reported. That such a small number of families have such a range of experiences and needs illustrates the heterogeneity of ASD and the fact that there is no single solution to the challenges families face: one size does not fit all. The needs of families with older children with ASD are diverse and vary according to the nature and severity of impairment from ASD and other disabilities, behaviour challenges, and available support from schools and services.

Parents, unsurprisingly, talked mostly about their children rather than family dynamics or their own behaviour, and it is important that parents, and their approaches to managing their children's disabilities, are supported. Nevertheless, it is also important to note that systemic approaches emphasise that the needs of families will also vary according to relationships and family dynamics: for example, that children's challenging behaviour should be understood in terms of the meaning of the behaviour to the child, the environment in which it occurs, the function and role of the behaviour, and its consequences (Howlin 1998). In other words, the relationships between children and parents, and the behaviour of parents, will also be important to determining the needs and strengths of families. This is a sensitive topic as ASD has historically been associated with 'parent (especially mother) blame', and parents are unlikely to recognise parenting or family behaviours as the most important intervention site when children's behaviour is aggressive or otherwise challenging. Nevertheless, a sole focus on the behaviour of children with ASD as 'the problem' is too narrow.

The overriding trend in best practice models of intervention is to consider the child and his or her environment in a holistic fashion. It is no longer acceptable to simply focus on a single challenging behaviour, no matter how difficult it may be for the adult care givers to cope with or manage that behaviour (Evans, Meyer & Buckley 2008).

### 4.1 Vulnerabilities

The ASD-related impairments that adolescents experience, as reported by parents, include challenging behaviour including aggression, anxiety, depression, loneliness due to poor social skills, and difficulties with school work and peers.

#### Challenging behaviour

Four parents spoke about the problems of having an adolescent who was physically aggressive. The behaviour described would not be classified as very severe on standardised scales—extreme tantrums, hitting and kicking parents, and breaking windows, but not injuries to self or others that required medical assistance—but it alarmed parents a great deal, especially because they feared it could get worse. Each of these parents spoke of needing an emergency plan to be used in situations where the behaviour of the child or young person became intolerable or unsafe. Calling the police is not regarded as a viable option. Three parents spoke of their reluctance to call the police even when their adolescent was out of control and hurting them.

We sort of need an emergency plan that is ... if he is harming you know us or his brothers, what do we do in that case? ... we don't have a backup plan on that. (Mary, parent, Vic.)

These parents also talked about strategies that they had used in trying to manage challenging behaviour, including isolating the young person, talking to them in a consistent controlled manner, or removing them from the situation. These strategies were not successful for all parents all the time, however, and the assistance of mental health professionals was sometimes essential.

All four families talked about the isolation the aggressive behaviour resulted in for the family. One mother spoke about not being able to care for her twins long term because of the difficulties of their behaviour. Of the four families, only one was receiving respite on a regular basis: this mother received one weekend a month. One family had considered respite but rejected it as they felt that the resultant behaviour would be even worse than current behaviour.

Although in all four families the children were on medication, this was seen as a last resort. (It is important to note that children in other families were also on medication as part of a broader therapeutic strategy.) Laura's daughter did not receive a diagnosis until 10 years of age and so she missed out on any early intervention. As with all the adolescents who were aggressive, Laura's daughter suffers from depression as well as being aggressive.

She smashed her window, smashed her bed. My younger daughter who's now 6 years old, her safety was in jeopardy. ... It was living hell. And so we ended up going to like the mental health outreach patients and now [daughter] is on medication, so things are a lot more manageable than they have been. (Laura, parent, NSW)

The use of behaviour interventions that work with younger children, such as encouraging communication skills, appears not to work with the families interviewed who were experiencing aggressive behaviour. One family found PECS (Picture Exchange Communications Systems) worked well at school but their son did not want to use it at home. Laura found Social Stories were rejected by her daughter. Tracy found that the Department of Education's behavioural support was not sufficient.

He refused to go [to school] and he had nothing to calm himself down and he became quite agro and attacked me. At this stage we got to the kids hospital and that's when we got help. (Tracy, parent, NSW)

Ten parents reported that their child had difficulties at school that resulted in poor behaviour. This is often due to not being able to write well or falling behind in a subject. Four parents talked about their child excluding themselves from school, due to poor transitioning and not coping with the larger school.

As the pressure of high school increases it appears that many adolescents become aggressive due to their anxiety. Two parents talked about their child's aggressive response to bullying. Due to the pressures of school four adolescents left school early.

### **Other behavioural issues**

Three adolescents refused to attend school either temporarily or permanently. The reasons for this, according to parents, relate to bullying and peer isolation. Tracy, from New South Wales, believed her son's refusal to attend stemmed from his awareness of his 'differences' from his peers, rather than bullying. One of the three adolescents who refused to attend school was attending special education. The other two were in mainstream classes where they struggled to keep up with their peers, were socially isolated from them and received poor understanding from their teachers. One parent felt that excluding her son from school for poor behaviour served as a reward that endorsed the effectiveness of poor behaviour.

Three parents found that interventions that worked at school such as pictorial timetables did not work at home. These adolescents did not want the structure at home that they received at school. In these cases parents found allowing the adolescent 'downtime' to be in their room and use the computer for games or social interaction in order to de-stress from the day allowed them time to 'recover' from school.

### **Social skills**

Fourteen of the parents interviewed highlighted social skills as their main need for their child. Social skills were not just about being able to talk to others, they were seen as improving their academic comprehension as well. Research has indicated that adolescents with ASD achieve below their capabilities (Ashburner, Ziviani & Rodger 2010), and nine parents believed their child's academic results did not reflect their academic potential.

Loneliness and social isolation recurred as parental concerns. It was clear from all the parental interviews that they perceived their child wanted friends and social interaction but did not know how to go about it. There was concern from four parents that there was the potential for exploitation as a result of the adolescents' neediness.

[M]y son is being bullied at school by a couple of kids and it's a ... this is ... he doesn't understand that they ... they say he's ... they are his friends ... well, definitely not his friends. But he doesn't understand what friends are and it's ... it's all that ... you know that's hard stuff. (Lisa, mother, Vic.)

He doesn't know how to talk to girls. He goes on the net, to our disgust, and goes onto the porno sites. And so he knows all there is to know about sex through porno sites. So he has no idea ... I mean, I tried to tell him that's not what a girl likes, he gets disgusted with me that I'm actually having the conversation. (Sharon, mother, NSW)

Five parents spoke of their children's awareness of their differences and only wanting to mix with other typical developing peers. The biggest concern for all the parents in our study was loneliness, isolation and the potential for depression. Indeed, peer acceptance was the reason parents had eschewed special education, preferring the general education system for their child.

Parents are faced with many decisions to make when a child transitions out of primary school into high school. Around this same time puberty begins and if behaviour problems have not been addressed in earlier times these can escalate considerably during puberty (Attwood 2006). Obsessive compulsive traits, self-harm, anxiety and depression are all potential problems in adolescents, especially if the adolescent views themselves as 'different' (Howlin 2004). The children themselves become more aware (Williams White, Keonig & Scahill 2007) and are at greater risk of social isolation.

Theresa commented:

I remember Tony Attwood saying that things aren't going well and in place for a young person with Asperger's, ... like 75 per cent of them have severe depression or anxiety. You know, a lot of them are severely depressed and suicidal, and self-harm and all sorts of issues like this we're seeing. Yeah, because they just feel so isolated but once again, really ... [They're] really aware that they're different and that their life is not so good. (Theresa, parent and service provider, NSW)

Social impairments include difficulties with turn-taking in conversation and understanding others' body language, tendencies to focus on single topics, and expressive language (Baron-Cohen 2001). One of the main areas that can ameliorate these problems is work on social skills. These include communication skills, reciprocal conversation, sex education and peer interaction. Social ability was the main area where adolescents with ASD were found to have the largest skills gap with their typically developing peers. In some cases this gap appeared to increase as social interaction became more complex with age, although it should also be emphasised that other young people developed techniques for managing their impairments and independent behaviour.

Twelve parents spoke of the need for ongoing social skills training, social peer mentoring and general connectedness with their peers. Eight parents linked their child's depression and anxiety to their loneliness. However, due to potential for exploitation, it was essential for any social activities to occur in a safe environment.

One effective social skills training reported by parents was based around ABA, peer support and video modelling, particularly with older adolescents and adults. Three service providers spoke about the importance of putting social skills training in place before social phobia or anxiousness took hold. One recommended that social skills training should commence in late primary school before children with ASD become aware of, and self-conscious about, being 'different'.

For school age, especially senior school, we're talking late primary and then high school, the issues become very difficult, very critical. And it's the, I think the main issue is the social isolation of the child, and that is such a key thing for these kids. And families are desperate for social support for their child. (Francis, service provider, NSW)

Three parents expressed a desire for 'mixed groups', that is, groups that included typically developing teenagers who could possibly provide empathetic support and assist with integration into school and other social situations. Many teenagers who were 'high functioning' or diagnosed with AS did not want to mix with other adolescents who had other intellectual problems such as Down's syndrome. These parents talked about social skills as essential for the teenagers.

For the most part, parents also talked about respite, not in terms of respite for them but in terms of the adolescent having respite from home, having activities that were interesting and challenging, and thereby becoming more confident.

Wouldn't that be wonderful that they had something set up so that these young people could go, even for a weekend, once every so often, and know that they're going to get the respite they need. They need the respite. (Sharon, parent, NSW)

One mother was concerned that while her son would be academically capable of tertiary studies, he would be unable to study due to his inability to interact with his peers.

## 4.2 Late diagnosis

Only two of the families reported that their adolescent had received early intervention prior to 5 years old, although others had been diagnosed young. Both had improved substantially, although one still has quite impairing traits. Perhaps unsurprisingly, most of those diagnosed at an older age were 'high functioning'.

The children of most of the parents we interviewed had received a diagnosis more than five years ago. One was diagnosed within the last 12 months, two had been diagnosed between one and two years ago, and one more than two and less than five years ago. Each of these parents described a gradual process and a fairly long time prior to diagnosis of realising something was 'wrong'. In two cases the children had received diagnoses other than autism some years ago (in one case the early diagnosis was of ADHD (attention deficit hyperactivity disorder), and this was recently identified as incorrect).

The process of diagnosis for these families appears to share commonalities with the families of young children interviewed for the main study, in that there were no direct links between diagnosis and treatment and parents needed to spend time and resources finding out the best course to take. One difference between diagnosis of older and younger children is that early intervention services tend to be unavailable for older children and in any case are not designed for them.

She was really too old [...] She's quite oppositional, so things like Social Stories, she just doesn't want a bar of it. And also she was just probably that little bit too old to really take to Social Stories. (Laura, parent, NSW)

Late diagnosis does not mean that intervention is not effective. With imaginative support, strategies can be put in place that reduce the triggers for poor behaviour and give the adolescent strategies to cope with triggers. Laura, for example, found a mental health worker who worked with the family and the home environment to reduce triggers for poor and potentially dangerous behaviour. By reducing the triggers the family have been able to manage the child's behaviours.

And there was really no service except for ... finally the acute mental health care team linked me up with a social worker that was sort of our support social worker where he would call me. He came to our home. That's the kind of service that we needed but that I searched for probably eighteen months to two years for. (Laura, parent, NSW)

Parents described needing to know the right questions to ask of services and clinicians, and services being difficult to use, 'unless you know what you are looking for' (Emily, parent, NSW). Three parents said that they sought a diagnosis because of their children's behaviour, and had to spend time and effort convincing clinicians that the behaviour really was problematic.

Sometimes the diagnosis was queried, such as with Meredith's son, where the school still believed that his problems were behaviour-related and not due to Asperger's. Even if the adolescent is of average intelligence, they still suffer from social deficits, behavioural difficulties or even sensory issues.

In one case, early intervention was not carried out and the person with ASD may suffer problems later in life. Freya, who cares for her granddaughter with ASD, also has an adult son not diagnosed until he was in his twenties. He is constantly in trouble with the law and drinks heavily. He is unable to work and has problems socialising.



A diagnosis, however late, may be a relief. Many adolescents with ASD are aware of their differences but are unsure why they are different.

I know of one young man who wasn't diagnosed until quite late into his teens, in fact early 20s I think and ... so he went through all of school not understanding why he felt so different and you know he had a lot of anger problems, he had a lot of anxiety and depression problems, he was pretty traumatised by the end of it and when he was finally diagnosed, in a way he was relieved. (Francis, service provider, NSW)

### 4.3 Parents' treatment decisions and approach

Although most of our participants worked while the child was at school, there were four mothers who were unable to work due to their adolescent's disability. This was due to being called to the school on a regular basis, trying to find appropriate services or providing additional educational support for their child. One adolescent was home schooled until Year 10, and one had since left school and did not have any options for work. One mother with twin girls, both with autism, found that due to their behaviour she was only able to do work well below her educational level in order to have flexible arrangements.

And you just can't ... you know, often families are one income because ... someone needs to be supporting their child. You know our kids can't just go on a bus ... to school you know. (Theresa, mother and service provider, NSW)

Funding is fragmented and dispersed for adolescents, and parents complain they had to have a great deal of time available to fill in application forms for whatever funding they had available. In part because of lack of information on support funding, some parents decide not to access therapies, rather leaving it up to the school to put behaviour intervention strategies in place to assist the child.

As we found in the main study, 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. For example, Chloe preferred all the therapies to happen in the school setting. This meant less driving around and also delivered the benefit of consistent approach of delivery. Chloe also described the importance of treatment meeting the needs of the whole family:

I've known a lot of mothers who've turned themselves inside out to try to find a cure practically for these children. I've just tried to go, whatever works for me—will it work for him primarily—but what will work for all of us? So a lot of it's been I suppose an emotional response, I've just gone well this is going to work, it looks good, we'll do it. (Chloe, parent, NSW)

Chloe describes her family's response as pragmatic. For other parents it seems necessary to spend significant resources in acting as a therapist and advocate for their children, even if this means turning themselves 'inside out'.

And so I just ring up the people who are organising the course and I say 'tell me about what you do, here's my circumstance, should I be part of it?' But I'm definitely driving it, I'm driving it with school, I'm driving it with the specialists. I'm trying to keep the specialists like the OT and the speech therapists, I'm trying to keep that all together because school is very much taking the view that 'we are the education' and in fact they're not, they're only one part of it. (Alyce, parent, Vic.)

Lisa runs workshops and mentors other parents:

This was two months sitting around a kitchen table discussing what we need in our community and addressing it and ... and going out and ... and getting it to happen. And making it happen on a voluntary basis and to think that I can see all these kids within our own community who are not getting their teachers and staff to come along and learn about you know these children that they've got. (Lisa, parent and service provider, Vic.)

One parent's attempts to work with a school broke down to the point where she felt she had no choice but to home school her child. In contrast, Maria describes her determination that her children, both with ASD, share their experience of school:

I want the kids to still have a good family togetherness, like it's pointless to send them to different schools when I'm involved and I want to be involved and I think they need that. And I don't want them to be one sex schools, I don't believe in that and I want them to be close enough to home that they can be independent. (Maria, parent, Vic.)

Maria and Lisa describe themselves, as other parents do, as 'nuisance' parents to schools and service providers, in their assertiveness and advocacy for their children's needs.

Four parents talked about chasing information. This included spending a great deal of time visiting services and requesting information on their waiting lists, range of services and appropriateness to their situation. This takes considerable time and often means the parent is limited in their work opportunities.

I've spent my time diving around trying to find what to get here, there and everywhere to help. (Samantha, parent, NSW)

Parents' responses to their children's symptoms also demonstrate diversity in the strategies families adopt. Mary, for example, describes managing behaviour by imposing strict boundaries on her child's activities when she recognises environmental or situational triggers. Chloe describes changing the environment and removing her child from distressing situations.

Samantha stopped using one centre because:

They wouldn't take him on once a week ... by the time I fitted in all his jolly sports and stuff there was no way I could fit in doing this, and sports was far more important to him than fixing up his English. (Samantha, parent, NSW)

Where fathers were actively involved, as in the main study, there was evidence that they were a major source of support. A few parents talked about the importance of acting as a team with their partners. Sharon, a parent from New South Wales, talks about consistency in behaviour management:

But we've learnt to back each other up. We've learnt that we don't contradict each other, and we have to stay calm. (Sharon, parent, NSW)

## 4.4 Support for siblings

Siblings of children with ASD have varying responses. Other research has found that the age of the sibling affects the way they respond to their siblings' behaviour (Pilowsky et al. 2004). The older the sibling, the less impact the autistic behaviours affected them. In one study, where the social and emotional adjustment of 30 siblings of children with ASD was compared with siblings of children with other intellectual and developmental disabilities, Pilowsky et al. (2004) found that almost 90 per cent of siblings were functioning well regardless of age. There was a correlation between the stress felt by the parents and the degree siblings of children with ASD were affected by the autism. There is evidence that older siblings go through similar emotional stages as the parents (Aksoy & Yildirim 2008). A UK study found that sibling relationships with a child with ASD were less compromised if the parental relationship was intact and not under pressure (Rivers & Stoneman 2003). How the older siblings responded to their sibling with a disability depended on parental attitudes and the personality of the child. Aksoy and Yildirim (2008) found that siblings of children with ASD found it harder to cope because the disability was less obvious and therefore caused more embarrassment than those where the disability was physical. Still other research indicates a risk of problems with language and speech of younger siblings (Tomblin, Hafeman & O'Brien 2003).

In this study four parents reported that their children without ASD suffered embarrassment or other problems because of the behaviour of their siblings. These ranged from being physically abused, not being able to give the sibling space to have friends over, and general noise and distraction for two who were studying for their final exams. Tracy and Mary both described the impact of ASD-related behaviours on the study of their older children without ASD:

She had a very hard time last year because all this, the violence stuff and the police coming happened during her [HSC] trials. And in fact when we took him to the kids' hospital it was during the trials, all the beds were taken so no help, so we had to bring him home and manage him. (Tracy, parent, NSW)

Trying to study and [younger child with ASD] doing the squealing and the very loud noises and the jumping up and down, you know [older child without ASD] sort of you know, hasn't been able to sort of have the patience to tolerate all of that. (Mary, parent, Vic.)

Younger children in particular appear to be most affected by the behaviour of older siblings with ASD. Chloe has two children with ASD, and reports that her children without ASD seem to be more affected by the ASD of the brother who is older than them, than the one who is younger. Parents reported trying to spend more time alone with the siblings of children with ASD, but none had applied for additional external support. Parents did express concern for the sibling where there was potential for aggression in particular towards that sibling. Laura says:

I'm worried about my younger daughter's self-esteem. She ... you know, she goes to school happily and she has friendships and things like that but I do worry about her self-esteem that her sister who ... you know, [child with ASD] is completely intolerant that she has a sibling. (Laura, parent, NSW)

However, two parents who had older children who no longer lived at home talked about the great bond the siblings had. Both these families used the older sibling for respite.

## 4.5 Post-school support

Transitioning from high school often appears to be problematic. There are a number of issues regarding transition. Relationships with Centrelink can be problematic due to the agency staff's lack of understanding of ASD. The parent has to prove that the young adult has a lifelong disability ('it's not mumps or measles': Meredith, a parent from NSW). Meredith felt she was having pressure on her to work despite being unable to due to her son not being in work or regular community activity.

Parents also need support in future planning for their adolescent. They need help deciding which option is best for them, including whether their child will be able to live independently, options for training and employment, and assistance with planning for that time. Three parents talked about a need for ongoing case management where a person would become familiar with the family needs and be able to assist them with sorting out behaviour intervention, and generally be a source of information and advice for the family.

[Y]ou know there's going to have to come a time where he's going to have to live elsewhere. And you know ... and I sort of say well you know, where's that going to be? And yeah, I ... yeah, we haven't gone down that track. And where does he go? [...] I suppose that's where a case manager comes into it, where you could just go to that one person and say hey, what's available out there? What ... what is out there? (Mary, parent Vic.)

Senior school can be an especially difficult time for children with ASD and their parents, as the typical turbulence of adolescence is compounded by the specific challenges of ASD. The prospect that their children will not be able to find work and so become financially independent can be acutely felt by parents at this time.

Sometimes the crisis sort of bubbles away beneath the surface, but often it erupts, and I think especially for senior school. And families are scared, parents are worried about the future. What's going to happen to their child once their child leaves school, and then what's going to happen with their child when they're no longer around. You know, what does the future hold. There's no certainty. All of the certainties are taken away. Their child may never marry and raise a family. (Fanny, service provide, NSW)

Although there is support for students with ASD in universities and life skills classes at TAFE, three parents of 16 year olds and above did not know about this. Information for transition to post-school options does not appear to be provided until Year 12, which is probably too late for many. Planning and information needs to be provided early on so that the supports are put in place to provide a seamless transition.

And so, what we'd like to do is get students that are like Year 10 at the latest, like when they're having to make career choices or Year 9 even and have them come over ... students with Asperger's, I mean, one day a week maybe, to TAFE. And we'd like to see ... a seamless transition like, working with the schools. (Theresa, mother and service provider, NSW)

Post-school options are available. TAFE in particular runs life skill classes for a range of disabilities. However, transitioning over to such classes needs careful preparation that accommodates anxiety and stress around change. Careful consideration needs to be given to how skills acquired at TAFE are generalised into the workplace.

And [Head Disability teacher] has been noticing that they're doing okay academically and getting their qualifications but then they're not transferring those skills across into the workplace. (Theresa, mother and service provider, NSW)

Information needs to include further education options, skills development and transition to work options. It also needs to include community activity centres and sheltered workshops for those who will be unable to work.

The sometimes lifelong impairments of ASD worry parents, both immediately post-diagnosis and as their children grow older. In part this is because of the uncertain nature of ASD's trajectory through the life course, in part because of the intensely socially disabling effects of ASD. The age at which ASD is diagnosed also affects the impact of diagnosis, according to a service provider:

When families come in with a baby with Down's syndrome, they don't look at that long-term thing. They're concerned with the baby, they've got a little baby, what do they do with the baby. Families, 'cause the kids are that bit older when they get that diagnosis of autism, they suddenly go 'oh my goodness, what's the long term picture?'

*Interviewer:* Yes, are they going to be able to get a job, get married?

*Interviewee:* Yes, and they become much more focused on that, looking at that whole of life thing, more than any other disability [...] a lot of families find that really stressful. (Trisha, service provider, NSW)

A few parents and service providers spoke of the need for resources to ensure that the specific vulnerabilities and skills of children with ASD are supported towards employment and social participation:

We want to run programs and we want to get them working. And they're not going to sit at home playing PlayStation in their parents' house until they're 45, it's just not going to happen, we need to get them working. And they can work, but there just has to be good supports, and that takes money. (Katrina, parent and service provider, NSW)

So many of the young adults with whom I work are in vocational training programs or with job search agencies, but they're always between jobs. (Fanny, service provider, NSW)

Life skills encompasses skills that most adolescents acquire gradually as they mature, such as managing money, sex education, preparing for interviews, becoming employment ready and general personal security. However, there is evidence that there is a certain level of naivety among adolescents with ASD. This means they have the potential to be vulnerable to exploitation. Four parents expressed concern over this vulnerability.

One of the key recommendations of the State Autism Plan of Victoria (State Government of Victoria 2009) is that, in order to improve transition processes, all services, schools, employment agencies and families work in concert with each other. Hendricks and Wehman (2009) reviewed the literature on transitions from school and recommend:

- a multidisciplinary approach to develop effective transition plans
- young adults themselves actively participate in the planning process
- training should start while the young person is still at school
- post-school services that assist with personal development as well as ensuring ongoing ASD behaviour-related support as required (Hendricks and Wehman 2009).

Hendricks and Wehman's (2009) review of the literature shows that community colleges are often better at providing transition training than schools. Decentralised community-based models using the full continuum of supports appears to improve life skills for young people with ASD in Florida. Transition planning should commence between 10 and 13 years of age, with more skill development commencing around 16 years. Hendricks and Wehman (2009) believe that active participation in the transition planning by the adolescent with ASD is essential.

## 4.6 Information and service gaps

### Information

Adolescents, especially those who have not had early intervention, need ongoing therapies such as speech therapy, occupational therapy and psychology. Parents with younger children can use the Raising Children Network website, but there is no one authoritative Australian website, which gives information on therapies, funding and support agencies in each state for older children and young people. This includes emergency support, behavioural therapists, psychologists and speech therapists that are skilled with adolescents.

I mean there is probably a lot of help there but how do you get it? (Tracy, parent, NSW)

The families of adolescents also need assistance with long-term planning, including post-school options, advice on housing and other post-school needs.

Funding support is available for adolescents to some degree, but it is fragmented across several different levels of government including non-government agencies and not coordinated. Four parents talked about having to know where to go for funding once the child reaches 11 years old. The Raising Children Network has an 'Autism Services Pathfinder' web page that assists parents through the options available for young children. A similar services pathfinder would be useful for adolescents. Evaluation research on the impact of autism advisors in each state will be especially useful if it includes their assistance for families with older children.

### Education and schools

Six parents reported that their children have a normal IQ but had fallen behind at school, and there was little support for them to improve. Three parents wanted more information on high schools, whether the school had experience with students who were on the autism scale or were open to learn. Parents need a school that is receptive to parental input and is prepared to liaise with the parent to improve the students' outcomes. Children and young people need schools that will include life skill programs, including social skills, managing money, travelling independently and otherwise participating in society. It seems particularly difficult to get information on mainstream schools with specific expertise with children with AS.

I was trying to find a secondary school that's mainstream that's skilled with children with Asperger's and I've been to I think about five people and nobody knows of anywhere. They're saying the only schools they have are you know where the children aren't high functioning and I don't want to put him into that. (Emily, parent, NSW)

I've asked over a number of years what ... what they'd recommend for [my son] because I know he's ... he's smart but he's not going to want to do the academic stuff, it's not what he wants, it's what other people might want ... want from him. (Maria, parent, Vic.)

Information is needed on both public and private schools, plus any details of additional support they offer, including life skills training, peer support and focused anti-bullying policies and practices.

### Service types

Information about and access to a range of services was identified by parents and service providers as particularly important for older children and adolescents, but often difficult for their families to find. These information and service needs demonstrate the diversity in type and severity of impairments associated with ASD, and the differences in service needs for younger and older children. They include the following.

#### *Mental health services*

Families need a wide range of these services, from early intervention psychological services for children who are vulnerable to anxiety and depression and mental health, to crisis intervention services for families under extreme pressure due to challenging behaviour.

I had this year of my life that I call my year of meetings, where every week I would have appointments to go and try and find support for our family [...] And really what it came down to was that the service we needed did not exist, except through acute mental health care. (Laura, parent, NSW)

Because there are few intensive services (in New South Wales, for example, there is one joint education and health facility for the treatment of children and adolescents who are experiencing emotional, behavioural or psychiatric difficulties), these services tend to have long waiting lists and time-limited access.

### *Social skills and social opportunities*

Service providers noted the effectiveness of appropriately delivered programs that enable young people to relax and engage with others. Parents and service providers also noted the need for accessible and engaging programs to develop social skills: as Lisa, a parent from Victoria, put it, ‘the older he gets the bigger the gap in social skills gets’. Friendships with neurotypical children appear to be valuable for those children with ASD who have them, but three parents expressed concerns at their children’s ability to manage friendship and social groups. The same number of parents also indicated that their children did not want to participate in activities with children with ASD or other disabilities. All this suggests that social skills ‘training’ is an identified need, but that the challenges of implementing an effective program are substantial. In contrast to speech or behaviour programs with young children, it is not only a matter of making trained practitioners available but also taking account of the complex and fluid nature of adolescent friendships and their mediation through formal and informal programs; and the risks and benefits of placing children with ASD with children without disability, or with children with disabilities other than ASD. Despite these challenges, parents reported several examples of successful courses and groups (see Section 4.7). When those groups are felt to be helpful, especially if children and young people enjoy them, the short-term or occasional nature of them can be a frustration for parents. Opportunities for social connection for most young people are not ‘rationed’ to six-week blocks.

[The state peak body] actually ran a program [...] which was empathy and communication skills, and it was run for about six weeks [...] on Thursday nights, and a couple of Saturdays [...] He loved it, couldn’t wait to get there. And it was because he was meeting with them, they were laughing, they were talking, they had, after, you know, they have soccer. [...] He was in company that accepted him. And I thought, well why can’t we do this all the time? Why can’t we have these things being run all the time? (Sharon, parent, NSW)

### *Educational and vocational services*

Educational and vocational services are services that enhance mainstream learning and employment environments, and make them suitable for children with ASD. Parents and service providers talked of the need for advocates or brokers to mediate between young people and their schools or workplaces, as fairly straightforward changes to environments may be all that is needed to enable people with ASD to use and develop their skills.

And they’re not going to sit at home playing PlayStation in their parents’ house until they’re 45, it’s just not going to happen, we need to get them working. And they can work, but there just has to be good supports, and that takes money. (Katrina, service provider/parent, NSW)

Without these services, however, misunderstandings and unsympathetic responses seem common, and can lead to severe disruptions to education and termination of employment.

[H]e was working at KFC, he was actually sent home [...] They’re just saying he wasn’t focused on the job and that was like the reason, and I said no, he has a disability. You know, he has ... he’s autistic. He needs you know someone to support him when he’s learning the job, you can’t just expect him to know the job straight away, like the first day. (Helen, parent, Vic.)

### *Respite services*

Children with challenging behaviour can exhaust and demoralise their parents, especially as they age. Informal support from extended family and friends is often unavailable for these families, and high-quality formal respite services were identified as the most appropriate service to meet their needs. A couple of parents identified

recreational camps for children (rather than residential care with unqualified workers, as some had experienced), as an effective model.

### *Crisis support*

Unlike a small child who has a tantrum or meltdown, an adolescent who lashes out may be a danger to themselves or to others around them. The family needs acute care at this time to, firstly, protect the adolescent so that they do not harm themselves and, secondly, ensure that the parents and siblings are protected. Crisis support needs to be a mixture of mental health intervention, respite and long-term behavioural intervention.

### **Choice and appropriateness of services**

Children and young people with challenging behaviour place particular strains on families. One of these is the absence of crisis intervention and respite services, which appear to be only rarely available unless the behaviour is very severe. Behaviour below the threshold for specialist intensive support services—that is, behaviour not defined as requiring high and complex support needs—can still have a substantial impact on family life, and parents may find that the support systems that are in place are inappropriate for their needs. Children whose challenging behaviour is restricted to specific environments, such as home, may not be at risk of suspension from school and so be ineligible for specialist services.

Although a small number (two of 13 parents) reported that their child's behaviour was severe enough that the welfare of other family members was threatened, extreme tantrums, including hitting, were reported by six other parents, and by service providers. In these circumstances parents did not find referrals to positive parenting courses to be appropriate, and wanted case management or crisis mental health services and tailored assessment and support.

Parents also discussed appropriateness of services in terms of age. As noted in Section 4.1, a couple of parents noted that the use of PECS and Social Stories at home were resisted by their children, partly because they associated these programs with early intervention for young children. Several participants also noted that the emphasis of ASD services on young children means that older children cannot get access to services that are age appropriate. Some children who had been diagnosed at a young age had received intensive early intervention services for which children were ineligible once they started school. The drop-off in service provision and support was noticed by three of these parents, who reported that once children enter school early intervention services tend not to be available or, more positively, that schools provide the necessary support. Even those ASD services that are not age or time limited seem to be less suited to older children. One parent reported the state peak body as being especially strong for young children and their families but less so for older children. Another, whose child was diagnosed at a later age, found that the peak body activities on offer were not suitable for her child.

Because my child got diagnosed so late I felt like we'd missed the boat for a lot of support and yeah, especially now, there's ... yeah, I really feel that big gap. There's really nothing specifically available for her age group and she wouldn't want to go bowling with ... you know, she'd be like, 'why would I want to do that mum?'. (Laura, parent, NSW)

Other parents of children who had been diagnosed at a young age reported that early intervention services were not readily available to them then. This is in contrast to young children more recently diagnosed, who can make use of early intervention services through the Helping Children with Autism package and who may benefit from greater practitioner and school awareness of ASD. Parents of older children then may feel as though they have missed out twice: first, when their children were young and services were less available than they are now, and second, by being denied access to new age-limited services.

[This] generation of the nought to 7 year olds [...] they've got so much funding, they might not think they have, but God they've got a damn lot more than we were given. And I think because like autism is so recognised now but before it wasn't and you know I think like we've missed that boat but I'd like to get a bit of, you know, slipstream from that boat [...] And to me when you look publicly and in the media and that it's like autism's cured at 12, and I'm so sick of that. (Louise, parent, Vic.)

They talk about doing all this early diagnosis but then they seem to forget about the older children that need help as well. (Hayley, parent, NSW)

Service providers also acknowledge the difficulty they have in providing for the very different needs of older and younger children.

I think that there's a big push in our organisation at the moment [which comes from a] response to the research in regards to the early signs of autism. And so, we're running a pilot program at the moment and we're looking at children between 12 months and under 3 years. (Monica, service provider, NSW)

Group programs to support behaviour change or build social skills are valuable for some children with ASD and their families. However, this is not universally true. It has been noted in research that parents of children with ASD may not find it appropriate to be classed with parents of intellectual disabilities as the disabilities are thought to be so different (Whittingham, Sofronoff & Sheffield 2006). Equally, older children with ASD may be uninterested in participating in social groups, either because they do not want to participate in groups, or because they are not interested in the social activities. Group programs for children with a range of disabilities may therefore not be appropriate for children with ASD or their parents.

More generally, **any** program for older children with ASD can only be effective if it is attractive to both the child and their parents. 'Proven' interventions will not work if, as our participants reported occurring, children refuse to go, or parents refuse to let their children attend. This is especially pertinent for older children and contrasts with our findings in the main study. A number of parents of very young children in that study reported being unable to continue with programs because their children were distressed and their behaviour was unmanageable, but young children tend to have much less say than their parents do about the activities in which they participate. Older children and adolescents generally have opinions about their needs, and the best ways of meeting them, that are independent of their parents' opinions and may in fact be opposed to their parents' opinions (this is of course true of all children, not only those with ASD). Parents may therefore identify a need for their child to participate in social or life skills courses, but if the course is not attractive to the child, then it is unlikely to be effective. Several parents identified conflict or at least a divergence of views between them and their child about appropriate activities after school and during school holidays, time spent on homework, and so on. Maria, for example, spoke about the tension between her child's need to relax in a familiar environment (familiar environments are especially valued by children with ASD) during school holidays and the demands of an intensive vacation speech therapy program:

By the end of the school term they're really whacked out [...] And then they just want to relax, and then you're putting them back into these sorts of skill courses. And then [child's name] will want to do his sort of thing and not be interrupted, you know, he'd prefer just to lounge around and relax in an atmosphere that he's comfortable in. (Maria, parent, Vic.)

This situation is in many respects a specific, or heightened, instance of a very typical challenge for adolescents and their parents, as it is quite usual for parents to place a higher priority on school or skills development than do their children. It demonstrates, again, the need for programs to be focused on family relationships and environments, and the aspirations of children as well as parents, rather than a narrow focus on specific, expert-defined deficits or problems.

Service providers and parents both described the importance of services that are appropriate and having alternatives if the first service they try does not work for them. Five parents discussed the need for specialist services to assist adolescents and adults with ASD find and maintain employment. Of these, three had been unable to use any of these types of services, but two talked about the unsuitability of available services for their children.



## 4.7 What parents find effective

### Early intervention

Six parents had used some sort of early intervention with their children prior to starting school. Of those four had had no or limited behaviour issues even though three had severe ASD symptoms, such as having limited verbal skills, ritualised behaviour and sensory issues. Five of the six parents reported considerable improvement in their child's development over time. One parent with twins with ASD and intellectual disability reported that they were toilet trained and would attend to their own self-care. All had tried to continue intervention, often changing intervention as necessary.

I suppose the thing I'd say more than anything else is do the intervention while they're still young, because I mean, he did speech pathology consistently and some occupational therapy from age three to about age 12 pretty well constantly. (Samantha, parent, NSW)

Just as with many parents of younger children with ASD, parents of older children found it was a trial and error approach to what proved effective. Five parents talked about the most effective support was having a social worker, psychologist or behavioural interventionist come to the home to work with the family in their environment. Often the intervention focuses on a specific behaviour.

We actually got some support through the Assist program, through Human Services and for the Circle Concept [a visual aid that provides a concrete way to talk about different types of relationships and what is normal and appropriate to each]. They worked with her on the Circle Concept, so that she wasn't going hugging everyone and things like that. (Freya, parent, Vic.)

Intensive and specialist services that integrate education and emotional and behavioural interventions, such as Redbank School in Western Sydney, were found to be very useful.

### Working with schools

Two families felt that working with the school to agree on interventions and approach was the primary need to improve support for their child. Six parents felt that there was little coordination between schools and support services. One parent reported that even though advice had been provided to the school, the strategies had not been implemented. Cooperation between the family and the school appears to be a successful strategy, where it can be achieved.

I've actually got my school transitioning him in fourth term from grade to grade because he needs that. And I write a social story every year to help him with his transition. And unless he gets that full you know fourth term of transition, he doesn't cope well with ... with the change. (Lisa, parent, Vic.)

### Behavioural intervention

Parents who had experience of one-on-one behavioural intervention found it effective. Maria uses a behavioural interventionist from the Royal Children's Hospital in Melbourne who provides her daughter with strategies to deal with her feelings, bullying at school and social interaction. Though effective the consultations are only fortnightly but could increase if behavioural problems increase. Maria also has attended the Learning Differences Centre at the Royal Children's Hospital, which she only found out about through another parent. Maria found that the strategies did not only have to be effective but fun. For example, an ASD-specific speech therapy program in school holidays was not fun and her daughter refused to attend.

Where behavioural intervention was available it was deemed invaluable. Emily, from New South Wales, had a behaviour interventionist specialist come to her home. The therapist and the family worked as a team to find solutions that suited their son as well as the family. It was working because the adolescent heard from 'an expert' how he should communicate his needs, and the family learnt techniques to encourage that communication. However, access to behaviour interventionists in rural areas was problematic, with one family seeing a behaviour therapist once a month, which was seen as totally inadequate.

Even severe behaviour such as aggressive behaviour towards a parent appears to be ameliorated. Three parents (all of girls) talked about behaviour support appearing to be having a positive effect on their daughter. All three parents talked about behaviour intervention providing their daughters with alternative strategies to communicate their wants and needs rather than using aggression.

[You] see that she's thinking twice nowadays, she has some other avenues to behave and she thinks, oh okay, I used to do this but now I've got ... I can do this or that and she's choosing a better response. (Lisa, parent, Vic.)

Three parents reported that their child needed psychological support from a worker who understood ASD and could develop a rapport with their child. It appears that access to such services, particularly in regional Australia, are limited and that families have to travel to major centres to access appropriately qualified services. Even then there is a heavy demand for experienced psychologists who are familiar with adolescents with ASD.

### **Drug therapy**

Seven families reported using their adolescent requiring drug therapy to assist with behaviour or depression. Four were on SSRI drugs for anxiety, obsessive compulsive behaviour and severe depression. Without the support of the drugs, all parents reported that the adolescent was unable to study or socialise.

He got terribly anxious as the teacher at school, the principal at school, he said he was like a rabbit caught in the headlights, you know, just startled all the time and anxious all the time. And we put him onto Prozac and it made a huge difference. (Chloe, parent, NSW)

Drug therapy tended to be used as a last resort with all seven families, when behaviour was failing to respond to psychological or other therapies. However, all reported that the impact on the adolescent's behaviour was positive. One parent described the impact of the drug therapy as 'getting my daughter's old self back'.

Drug therapy as a means of controlling behaviour appears to be considerably higher in adolescents than in younger children (Goin-Kochel, Myers & Mackintosh 2007). The majority of the families interviewed were using some sort of anxiety or antidepressants for their son or daughter. The benefits were found to include improved concentration, less anxiety and less aggression. However, four parents reported increased appetite and large weight increases, with risperidone in particular.

### **Social skills training**

Research indicates that social skill groups are only marginally effective when delivered in isolation, especially for non-school-age children. There appears to be some efficacy in social groupings for school-age children where there is follow-up and reinforcement within the school setting. However, follow-up from a number of studies shows that constant reinforcement of skills are required to make acquired skills effective (Reichow & Volkmar 2009; Williams White, Keonig & Scahill 2007). Good social skills are also important to enable the adolescent to achieve their potential at school (Ashburner, Ziviani & Rodger 2010). Williams White, Keonig and Scahill (2007) point out that social deficits should not be confused with lack of interest in social relationships. Their survey of the literature found the following promising practices:

- increase self-motivation by increasing self-awareness and improving self-esteem
- increase social initiation by teaching social rules and age-appropriate initiation skills
- improve social responses by role playing and reinforcement
- promote skills generalisation by engaging with peers, multiple trainers and parents

Five parents talked about how important it was for their son or daughter to belong to a social group or participate with peers in activities. Of her son, who is vision impaired and has AS, Mandy said:

Vision Australia used to have a school camp. Funding cut that out. [child's name] loved the ... the Vision camp. He loved it. ... And we loved [him] going on that vision camp because that was a week of respite for us. (Mandy, parent, NSW)

Samantha's son had done social skills training through a centre-based ABA service provider in Sydney, and then through a separate group. She said that this training was the single most useful thing that her son did during adolescence.

Some schools provide imaginative social skills programs. Chloe's son attends a private school that has a strong philosophy of nurturing children. She found that the school ran social skills training that anyone could attend:

They do it in a way that is not damaging but makes the child understand because as they say look, you know, in the real world talking to yourself on the street is not acceptable. So they've got to learn not to do it, you know. And so they don't mollycoddle them at all, you know, they're clever and some people probably wouldn't like that. Personally I think it's fantastic because [...] the kids are happy. (Chloe, mother, NSW)

Two parents spoke about the support the Scout Movement has provided in social skills. Both experienced excellent scout leaders who were able to integrate the child with ASD into the group using peer support. One mother spoke of her son going away on camps and acquiring a lot of bush skills. The supervised environment had allowed the child to increase their confidence and independence. It had also allowed them to interact with typically developing peers in a safe environment.

One mother had utilised their son's love of computer games to take him to a games store on a weekly basis. Here he was forced to socialise with other gamers and it gave her a couple hours of respite to shop by herself. Indeed the computer can be utilised cheaply to provide communication through safe chat rooms. Theresa, a parent and service provider in NSW, had established a chat room for her TAFE students.

Utilising natural interests and skills appears to be a good way of providing social interaction. A grandmother in Victoria utilises her granddaughter's love of her dog to get her to attend dog handling classes; Chloe has encouraged her son's interest in karate to get him to attend competitions.

### Parental training

Six parents reported that they regularly attended workshops on a variety of themes associated with ASD. These range from Professor Tony Attwood's workshops to tips on providing support in school. Many of these workshops appear to be run by the parents themselves. In regional Victoria a couple of mothers have banded together to host workshops, mainly around parental training for managing poor behaviour.

### Information and support groups

One mother in regional Victoria has set up an information centre for parents in cooperation with other mothers. The support agency runs a mixture of workshops, coffee mornings and peer support for parents of children with ASD. The agency finds out about schools and agencies that provide support for children with autism. As a result the agency gets good support from the Victorian Department of Human Services. This type of agency is the sort of support most families need. It provides a mixture of resource information, advice and information as well as workshops. In particular, the information is relevant to the local families.

Asteen, a support group in south-western Sydney, is a group of parents who provide ad hoc information and support to parents through meetings and email. Two parents found this group particularly useful when dealing with particular issues such as how and when to deliver sex education. As well as support from partners, many parents found support from other parents useful. This appears to be the main source of support. For Sharon it is her main source of advice and information:

[T]hey just use it to keep in touch or find out what's on, or if something's on, they'll post it on the net, so that you ... they'll give you ... you can follow through with that, so that's mainly where I get my information. (Sharon, parent, NSW)

## 4.8 Conclusion: summary of recommendations

This section summarises the recommendations for changes to service delivery and support, as described by our interview participants and implied by the literature review.

### Behaviour support

- Just as with early intervention there needs to be support for adolescents with ASD. Support needs to be targeted at both those who were diagnosed in early childhood and those who have only recently been diagnosed with ASD, and should include behaviour and social interventions according to their needs.
- For a small minority access to emergency care is required. This would probably revolve around the mental health team and would include follow-up strategies including behaviour support within the home. Emergency support needs to be available 24 hours a day, providing a mixture of telephone support through to harm intervention teams who can provide alternate accommodation when the adolescent is at risk of harming themselves or others.
- Intensive multidisciplinary behaviour intervention programs are highly valued by those who have experienced them. These include the programs offered by Redbank School Westmead, NSW and the Learning Differences Centre at the Royal Children's Hospital, Melbourne.
- Behaviour Intervention Teams such as those provided by the Department of Human Services in Victoria are able to work with the family in their home. Support initially needs to be frequent and consistent.
- For some families, ready access to a full support team of behavioural therapists, psychologists and social workers may be required for the period, particularly during puberty when new difficulties sometimes arise.
- Families with complex needs require case management services. Case managers would put families in touch with appropriate services and provide ongoing support.

### Life skills

- Life skills training, such as that run at TAFE, should be offered to students from junior high school and extend to job training opportunities.
- Supported business enterprises need to be gender, age and skill appropriate to be attractive to people with ASD and their families. The presence of supported employment services in an area does not guarantee it will be useful to families, and in any case these services appear to be few in number.

### Social skills

- In general there appear to be social skills courses run in most cities. However, in several instances they are one-off and time limited. Social skills need to be reinforced on a regular basis to create competence and confidence.
- A wide range of social skills workshops, including those involving neurotypical peers and those that offer the opportunity to 'graduate' into social clubs, are likely to be successful. Programs must be attractive for adolescents as they are likely to refuse to go if not. Examples of this are the use of drama in the Social Skills program run by Autism Spectrum Australia (Aspect) New South Wales.
- Support needs to be provided for other social clubs and community activities, such as scouts and drama clubs, which provide a safe environment for adolescents with ASD to practice their social skills and acquire new friendships. Additionally, access needs to be provided to vacation courses that are residential to provide intensive social skill training. Vacation classes could include adventure courses that improve confidence. These clubs use the activities of music, film creation and running a newspaper to teach social skills. The clubs are staffed by staff with ASD experience but are essentially run by the adolescents.

**Access to timely and authoritative information**

- ▶ Access needs to be provided to information similar to that on the Raising Children Network, which is aimed specifically at adolescents aged 11 years and over. This would include a list of available services in each area for adolescents including late diagnosis, and funding availability.
- ▶ Drug therapies, especially SSRIs for anxiety and antipsychotics for behaviour, appear to be more commonly considered and used than most Australian ASD information sources would indicate. Information on benefits, contraindications and possible side effects should be available at popular ASD information sites, including Raising Children Network's 'Helping Children with Autism (HCWA)' web page.

**Funding**

- ▶ A comprehensive list of funding availability and the criteria for accessing that funding, both at federal and state levels, is required. Information should be made available through schools as well as through websites such as the Raising Children website.
- ▶ Development of an ongoing package of therapy availability similar to the Australian Government early intervention program, to provide financial support for ongoing therapy and psychology for adolescents, is needed.

**Integrated education and support environments**

- ▶ There appears to be a need to create an environment where teachers, family and therapists cooperate and communicate to apply a level of consistency of approach across all areas of the adolescent's life. One example of this, described by one parent, is the not-for-profit Joseph Varga school in Sydney for children with learning disabilities, conduct disorders and/or emotional disturbances.

**Respite**

- ▶ This research showed there were only a few families requiring respite. These tended to be single parents, or cases where there were severe behavioural problems. Respite needs to range from a few hours a week, through to extended respite over weekends for more intensive cases.
- ▶ Vacation-based respite that combines social skills training with adolescent-appropriate activities was highly valued by those parents who had experience of it.



## List of shortened forms

ABA	Applied Behaviour Analysis
ADHD	Attention deficit hyperactivity disorder
AIHW	Australian Institute of Health and Welfare
APPGA	All-Parliamentary Party Group on Autism
AS	Asperger's Disorder
ASD	Autism Spectrum Disorder
CBT	Cognitive Behaviour Therapy
CSTDA	Commonwealth State/Territory Disability Agreement
DEEWR	Department of Education, Employment and Workplace Relations
DET	Department of Education and Training (NSW)
HFA	High functioning autism
HREC	Human Research Ethics Committee
LEA	Local Education Authority
NAS	National Autism Society (UK)
PECS	Picture Exchange Communication System
SEN	Special Educational Needs
SSRI	Selective Serotonin Reuptake Inhibitors
SST	Social Skills Training
TEACCH	Treatment and Education of Autistic and Communication related handicapped Children
ToM	Theory of Mind
TSP	Transition Support Programme





## Endnotes

- 1 These figures are the numbers of people with a primary diagnosis of autism. They do not include those whose primary diagnosis is another disability, but for whom autism is a 'significant other disability'.
- 2 National Transition Support team website: <<http://www.transitionsupportprogramme.org.uk>>.



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# Occasional Papers

1. *Income support and related statistics: a ten-year compendium, 1989–99*  
Kim Bond and Jie Wang (2001)
2. *Low fertility: a discussion paper*  
Alison Barnes (2001)
3. *The identification and analysis of indicators of community strength and outcomes*  
Alan Black and Phillip Hughes (2001)
4. *Hardship in Australia: an analysis of financial stress indicators in the 1998–99 Australian Bureau of Statistics Household Expenditure Survey*  
J Rob Bray (2001)
5. *Welfare Reform Pilots: characteristics and participation patterns of three disadvantaged groups*  
Chris Carlile, Michael Fuery, Carole Heyworth, Mary Ivec, Kerry Marshall and Marie Newey (2002)
6. *The Australian system of social protection—an overview (second edition)*  
Peter Whiteford and Gregory Angenent (2002)
7. *Income support customers: a statistical overview 2001*  
Corporate Information and Mapping Services, Strategic Policy and Knowledge Branch, Family and Community Services (2003)
8. *Inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*  
Commonwealth Department of Family and Community Services submission to the 2003 House of Representatives Standing Committee on Ageing (2003)
9. *Inquiry into poverty and financial hardship*  
Commonwealth Department of Family and Community Services submission to the Senate Community Affairs References Committee (2003)
10. *Families of prisoners: literature review on issues and difficulties*  
Rosemary Woodward (2003)
11. *Inquiries into retirement and superannuation*  
Australian Government Department of Family and Community Services submissions to the Senate Select Committee on Superannuation (2003)
12. *A compendium of legislative changes in social security 1908–1982*  
(2006)
13. *A compendium of legislative changes in social security 1983–2000*  
Part 1 1983–1993, Part 2 1994–2000  
Bob Daprè (2006)
14. *Evaluation of Fixing Houses for Better Health Projects 2, 3 and 4*  
SGS Economics & Planning in conjunction with Tallegalla Consultants Pty Ltd (2006)
15. *The ‘growing up’ of Aboriginal and Torres Strait Islander children: a literature review*  
Professor Robyn Penman (2006)
16. *Aboriginal and Torres Strait Islander views on research in their communities*  
Professor Robyn Penman (2006)

17. *Growing up in the Torres Strait Islands: a report from the Footprints in Time trials*  
Cooperative Research Centre for Aboriginal Health in collaboration with the Telethon Institute for Child Health Research and the Department of Families, Community Services and Indigenous Affairs (2006)
18. *Costs of children: research commissioned by the Ministerial Taskforce on Child Support*  
Paul Henman; Richard Percival and Ann Harding; Matthew Gray (2007)
19. *Lessons learnt about strengthening Indigenous families and communities: what's working and what's not?*  
John Scougall (2008)
20. *Stories on 'growing up' from Indigenous people in the ACT metro/Queanbeyan region*  
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21. *Inquiry into the cost of living pressures on older Australians*  
Australian Government Department of Families, Housing, Community Services and Indigenous Affairs submissions to the Senate Standing Committee on Community Affairs (2008)
22. *Engaging fathers in child and family services: participation, perception and good practice*  
Claire Berlyn, Sarah Wise and Grace Soriano (2008)
23. *Indigenous families and children: coordination and provision of services*  
Saul Flaxman, Kristy Muir and Ioana Oprea (2009)
24. *National evaluation (2004–2008) of the Stronger Families and Communities Strategy 2004–2009*  
Kristy Muir, Ilan Katz, Christiane Purcal, Roger Patulny, Saul Flaxman, David Abelló, Natasha Cortis, Cathy Thomson, Ioana Oprea, Sarah Wise, Ben Edwards, Matthew Gray and Alan Hayes (2009)
25. *Stronger Families in Australia study: the impact of Communities for Children*  
Ben Edwards, Sarah Wise, Matthew Gray, Alan Hayes, Ilan Katz, Sebastian Misson, Roger Patulny and Kristy Muir (2009)
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