# A Guide to Identification, Diagnosis and Treatment of Autism Spectrum Disorder in Victorian Mental Health Services

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# A Guide to Identification, Diagnosis and Treatment of ASDs in Victorian Mental Health Services

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## Outline of the Guide

The guide has been designed to allow the reader to refer directly to information on one of the key developmental stages (early childhood. childhood, adolescence, adulthood). As such, there is some replication of information in sections three to six. However, readers are encouraged to read beyond the sections that relate directly to their current work to allow an understanding of the changing needs of individuals with an ASD and their families throughout the lifespan.

### Section one

This section gives a brief outline of why the guidelines have been developed and how they should be used. It describes the federal and state charters and acts that the guidelines are based on. The section also describes the five key principals that underpin the guidelines and provides an overview of the Victorian service system for individuals with an ASD and their families.

### Section two

Section two provides an overview of ASDs, intellectual ability and cognition, medical and mental health and associated conditions.

### Section three

Section three provides information about identification and referral, assessment and diagnosis, intervention and education and other considerations during the child's preschool years.

### Section four

Section four provides information about identification and referral, assessment and diagnosis, intervention and education and other considerations during the child's primary school years.

### Section five

Section five includes information about identification and referral, assessment and diagnosis, intervention and education and other considerations during the adolescent years.

### Section six

Section six includes information about identification and referral, assessment and diagnosis, intervention and education and other considerations during adulthood.

### Jargon Buster, Glossary of Terms and References.

## Contents

### Section one

### Section two

### Section three

### Section four

### Section five

### Section six

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# SECTION ONE

## INTRODUCTION

The guide has been designed to promote better outcomes for individuals with an Autism Spectrum Disorder (ASD) in Victoria across the lifespan. The guide draws on the best available information on assessment, diagnosis and intervention from the literature to encourage Child and Adolescent Mental Health Services (CAMHS) or Child and Youth Mental Health Services (CYMHS) to measure their actions and improve practice. The guide also provides current information on assessment, diagnosis and intervention in Victoria to assist CAMHS/CYMHS practitioners make informed decisions. The guide should be used in conjunction with parent values, knowledge and cultural perspectives and professional judgment and expertise. The guide does not provide specific recommendations for treatments, education or interventions, nor is it intended to be a directory of services. However, resources and access points for key services are provided.

The guide has been written at a time of change as CAMHS/CYMHS move towards service provision for individuals 0-25 years. Therefore, the guide includes material on early childhood, childhood, the adolescent years and adulthood with a view to considering the importance of continuity of care. Another significant change at this time relates to the revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM) due to be published in May 2013. As this guide for CAMHS/CYMHS has been written prior to the publication of DSM-V, the terms ASDs and ASD is used to refer collectively to individuals meeting criteria for Autistic Disorder, Asperger’s Disorder and Pervasive Developmental Disorder-Not Otherwise Specified as defined in the DSM-IV-TR (2000). When a distinction between these conditions is important, the specific term is used. Importantly, information about the proposed changes in the forthcoming DSM-V has also been included.

Guideline updates will provide current information on broad issues such as the changes to DSM, and government policy, as well as changes to Victorian ASD service provision and key contacts.

The guidelines are in line with Commonwealth and Victorian acts and charters. The guidelines also complement the principles and objectives outlined in the Victorian Government's State Disability Plan (2002-2012), Mental Health and Reform Strategy (2009), the Cultural Diversity Plan for Victoria's Specialist Mental Health Services (2006) and Autism Victoria's (amaze) Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of ASDs (2010).

### Victorian Disability Act

The Victorian Disability Act (2006) provides for a stronger whole-of-government, whole-of-community response to the rights and needs of people with a disability, and a framework for the provision of high quality services and supports for people with a disability. The act focuses on enabling people with a disability to more actively participate in the life of the community.

http://www.dhs.vic.gov.au/for-individuals/disability/your-rights/disability-act-2006

### Victorian Charter of Human Rights and Responsibilities

The Victorian Charter of Human Rights and Responsibilities (2008) which outlines twenty basic rights that promote and protect the values of freedom, respect, equality and dignity.

http://www.humanrightscommission.vic.gov.au/

### National Disability Strategy

The Council of Australian Government's National Disability Strategy (2010) has been endorsed by federal and state governments. The ten-year strategy is a national approach to enabling people with a disability to fulfil their potential and participate as equal citizens in society.

http://www.coag.gov.au/coag_meeting_outcomes/2011-02-13/docs/national_disability_strategy_2010-2020.pdf

### Victorian State Disability Plan (2013-2016)

The Victorian state disability Plan comprises three documents that are a resource and guide to the plan's vision of an inclusive Victorian society that enables people with a disability, their families and carers to fulfil their potential as equal citizens. The plan comprises four goals:

1. A strong foundation in life
2. Upholding rights and promoting participation
3. Accessing information, transport, building and places
4. A contemporary approach through disability system reform

www.dhs.vic.gov.au/statedisabilityplan

### Victorian Mental Health Reform Strategy (2009-2019)

The four core elements of reform are:

1. Prevention
2. Early Intervention
3. Recovery
4. Social inclusion

http://www.health.vic.gov.au/mentalhealth/reformstrategy/documents/mhrs_sip.pdf

### Cultural Diversity Plan for Victoria's Specialist Mental Health Services (2006)

This document provides a framework for improving mental health service accessibility and responsiveness to Victoria's culturally and linguistically diverse communities including:

1. Background information about Victoria's culturally and linguistically diverse
2. Communities and their rights and mental health needs
3. Examples of good practice in the delivery of mental health services to people from non-mainstream cultural groups
4. Strategies and actions for further developing mental health services' capacity to meet the needs of people from diverse cultural backgrounds.

http://www.health.vic.gov.au/mentalhealth/publications/cald-strategy.pdf

**Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders (2010)**

The guidelines provide assessment standards and guidelines for children, adolescents and adults, and lists eligibility criteria for government funding.

http://www.amaze.org.au/uploads/2010/11/ASD-Diagnosis-Assessment-Guidelines-Victoria.pdf

## KEY PRINCIPLES

The ASD guidelines are based on five key principles of child & family adjustment & wellbeing; lifelong support; collaboration, coordination and transition support; family centred practice; and evidence based practice.

### 1. Child & family adjustment & wellbeing

ASDs are serious neuro-developmental disorders that present in the first years of life and are characterized by impaired social interaction and communication skills and restricted, repetitive and stereotyped behaviour. Intellectual disability, medical conditions and mental health problems frequently co-occur, and while symptoms change over time, the majority of individuals with an ASD need individualised support throughout life (Amiet et al., 2008; Boelte & Poustka, 2000; Bradley, Summers, Wood & Bryson 2004; Fombonne, 2005; Gadow, DeVincent, Pomeroy & Azizian, 2004; Gilchrist et al., 2001; Gillberg & Billstedt, 2000; Howlin et al., 2004; Howlin, 2005; Rutter, 1983; Seltzer et al., 2003; Sverd, 2003; Tuchman & Rapin, 2002; Tonge & Einfeld, 2003; Volkmar & Klin, 2005). As the aetiology of ASDs has not yet been determined in most instances, there is no single or universally effective treatment for these complex conditions. The type and amount of support will vary between individuals, and over time.

Parenting a child with an ASD almost inevitably has a significant impact and can contribute to parental stress and mental health problems and can have adverse effects on family functioning (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Yim, Moon, Rah & Lee, 1996; Tonge et al., 2006, Pisula, 2007; Schieve, Blumberg, Rice, Visser & Boyle, 2007). Although parents of children with developmental disabilities may be at increased risk for psychological distress, they also report positive experiences (Bayat, 2007; Blacher, Baker, & MacLean, 2007; Hastings et al., 2005; Hastings & Taunt 2002; Helff & Glidden, 1998; Lloyd & Hastings, 2008). Whilst families, and individual family members, may respond differently from each other, the level, nature and quality of social support available to families has been found to be critical to their positive adaptation (Dunn et al., 2001; Hare, Pratt, Burton, Bromley & Emerson, 2004; Henderson & Vandenberg, 1992; Wolf et al., 1989). The provision of information, support and education programs to parents of children with an ASD can also contribute to positive child and parent outcomes (Bristol &

Schopler, 1983; Bristol, 1984; Koegel, Symon & Koegel, 2002; Schultz, Schmidt & Stitchter, 2011; Sofronoff & Farbotko, 2002; McConachie, Randle, Hammal & LeCouteur, 2005; Moes and Frea, 2002; Tonge et al., 2006; Whittingham, Sofronoff, Sheffield & Sanders, 2009).

These guidelines incorporate the biological, psychological and social aspects of care, education and support. Child and family adjustment and wellbeing and the provision of information on assessment, diagnosis and intervention for individuals with an ASD are addressed in the guidelines in four streams:

**i)** Identification & referral

**ii)** Assessment & diagnosis

**iii)** Intervention & education

**iv)** Other considerations: e.g. transitions, physical & mental health, intellectual ability

## 2. Lifelong support

Research has shown that whilst for some there is a reduction of symptoms over time, the majority of individuals with autism remain dependent on others throughout life (Billstedt, Gillberg, & Gillberg, 2005; Fombonne, 2003; Howlin et al., 2004; Nordin & Gillberg, 1998). Individuals with an ASD, and their families, require consistent, respectful, supportive, co-ordinated care and a range of services that reflect their changing needs throughout life.

In line with key developmental stages and current service provision in Victoria, four stages are identified in the guidelines. These stages should be streamlined through a focus on service collaboration, coordination and a planned approach to transitions.

| | | |
|---|---|---|
| **i)** | Early childhood | (The pre-school years) |
| **ii)** | Childhood | (The primary school years) |
| **iii)** | Adolescence | (The secondary school years ) |
| **iv)** | Adulthood | (The post school years) |

## 3. Collaboration, coordination and transition support

Individuals with an ASD, parents and professionals often experience difficulties when services are poorly coordinated or fragmented. Service coordination can be implemented at both a systems level (services promoting linkages such as developing inter-agency agreements) or at an individual family level (the development of an Individual Family Service Plan or nomination of a Case Coordinator or Key Worker).

Parents of children and young people with an ASD often have to deal with a significantly larger number of medical, education, mental health and allied health professionals than others. They may have regular interactions with the universal service system, such as kindergarten, school and maternal and child health. They may also have contact with specialist services such as paediatricians, disability services, allied health and mental health practitioners. Tertiary and acute services such as Child & Adolescent Mental Health Services (CAMHS/CYMHS) may also be accessed. These professional services are complemented by the informal care and support provided by the broader family, friends and community. Parents are often faced with the competing demands of this broad range of services and may have difficulty comparing their options. Some families experience additional stress when there is a lack of communication between professionals, conflicting advice, and the knowledge that current services may be withdrawn (Glenn, 2007). A collaborative partnership between parents, professionals and the child or young person with an ASD is critical to the provision of appropriate support and services.

Additional stress is also present for individuals with an ASD and their families during times of transition. Some of the most significant transition points for an individual with an ASD are when they move through different stages of development (e.g. adolescence) and education (e.g. home to early childhood education and care, kindergarten to primary school, primary to secondary school and secondary to post school options). National and international best practice guidelines highlight the importance of a planned approach and provision of appropriate supports during times of transition for individuals with an ASD (Department of Human Services, 2009; Manitoba Education, 2005; Howlin, 2004; National Autistic Society 2002; Office of Special Education & Rehabilitation, 2006).

## 4. Family Centred Practice

A common recommendation from all of the international guidelines on ASDs treatment and interventions is that family involvement and support is critical and that parents and professionals should work together to develop appropriate interventions (Dawson & Osterling, 1997; Francis, 2005; Howlin, 1998; Jordan et al., 1998; Kanthor et al, 1999; Le Couteur, 2003; National Research Council, 2001; National Autism Centre, 2009; Osbourn & Scott, 2004; Perry & Condillac, 2003; Roberts & Prior, 2006; Rogers & Vismara, 2008; Simpson, 2005). With a growing research base, family centred practice has increasingly become the philosophical foundation of many education, health care, therapy and autism specific programs and services. Family centred practice describes an approach to working with families that recognises that *how* intervention is provided is as important as *what* is provided (Trivette & Dunst, 2000).

Family centred practice includes:

- treating family members with dignity and respect
- building on the families' strengths
- sharing information so that families can make informed decisions
- individualised and flexible practices
- promoting parent-professional partnerships

(Dempsey & Keen, 2008; Dunst, 2002; Espe-Sherwindt, 2008; Gabovitch & Curtin, 2009; Shelton & Stepanek, 1994).

The Victorian Government Department of Health (DoH), in partnership with the Department of Education and Early Childhood Development (DEECD) has developed a suite of seven family-centred, person-centred, practice guides. The guides aim to support people who work with children, adolescents and young adults with a disability (or developmental delay) to work in more family centred ways. The guides have been developed for educators, respite and disability support workers, allied health practitioners, early childhood intervention professionals, case managers and other professionals involved in the lives of children and young people and their families.

http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/family-centred-practice,-person-centred-practice`

## 5. Evidence Based Practice

Research on treatments and interventions should inform parents, practitioners and policy makers about practices that produce positive short-term and long-term outcomes for individuals with an ASD and their families. An evidence-based approach has been central to medical practice for some time now, and has been defined as "the integration of best research evidence with clinical expertise and patient values" (Sackett, Strauss, Richardson, Rosenberg & Haynes, 2000, p. 1). The American Psychological Association (APA) defined evidence based practice as the "integration of the best available research and clinical expertise within the context of patient characteristics, culture, values and preferences" (APA, 2006, p. 273). More recently, the National Autism Centre's report on evidence-based practices in schools (2011) stated that research findings should be integrated with:

- professional judgment and data-based decision making
- values and preferences of families, including the individual with an ASD whenever feasible
- capacity to accurately implement interventions.
-

Furthermore, the NAC report states that:

> "Evidence-based practice is complex and requires both ongoing communication and respectful interactions among stakeholders. Even when a list of effective treatments is identified, collaboration is the key to achieving the best outcomes" (NAC, p. 2).

## THE SERVICE SYSTEM

In Victoria, there are a broad range of professional supports and services provided by:

1. *Federal, state and local governments*

As well as providing direct service, federal and state governments also provide funding to community based and private services to enable them to provide a range of supports (e.g. Specialist Children's Services, Mansfield Autism Statewide Services, Amaze…)

2. *Community based services*

Community based services generally receive funding from a range of sources including governemnt, philanthropic trusts and donations (e.g. Association for Children with a Disability, St Lukes…).

3. *Private services*

Private practices may also receive some funding from government which partly subsidise their sevice (e.g. Medicare rebate, Helping Children with Autsim (HCWA) funding…)

Services delivered from these three sources (government, community based & private) are provided in three tiers:

1. *Primary: Universal services*

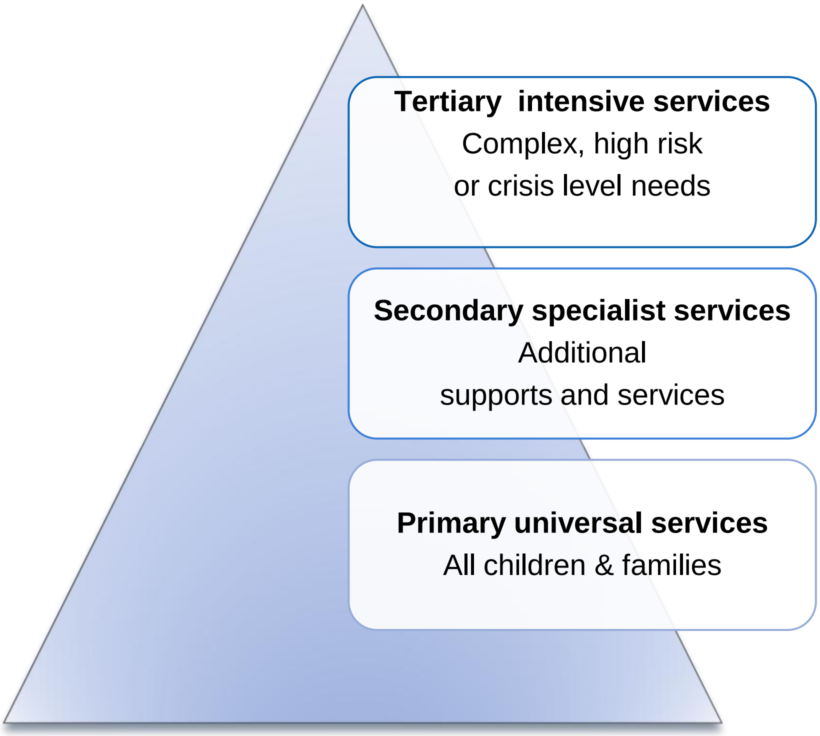
Available for all Victorians (schools, hospitals, neighbourhood centres, playgroups…)

2. *Secondary: Specialist services*

Available for those who require additional supports and services (e.g. Early Childhood Intervention, Speech Pathology…)

3. *Tertiary: Intensive services*

Available for those with complex, high risk or crisis level needs (e.g. CAMHS/CYMHS, inpatient units…)



These professional services are complemented by the informal care and support provided by family, friends and the community.

Most programs have eligibility criteria based on:

1. *Age* (e.g. Early Childhood Intervention Services: 0-6 years, Adult Mental Health services: 16-64 years)

2. *Diagnosis* (e.g. Irabina Childhood Autism Services: ASD diagnosis)

3. *Geographical location* (e.g. Mansfield Autism Statewide Services: Rural families)

Whilst all of these services are there to provide support, parents and carers sometimes refer to the service system as “a maze”. In response to this, some state-wide and regional directories and information lines have been developed and have been noted with thin the ASDs guidelines.

**Supports and services**

- The Association for Children with a Disability has developed a resource guide of services and supports for parents of children (0-18 years) with a disability titled ‘Through the Maze’ (2011). Many of the key contacts are also relevant for parents of young people and adults with a disability. Information is available in many community languages. http://www.acd.org.au/information/ttm.htm

- The Victorian State Government’s Department of Human Services has an ‘Intake and Response Service’ which provides information about supports and services to people with a disability, their families and carers. http://www.dhs.vic.gov.au/for-individuals/disability/start-here/access-to-disability-supports

- Amaze (Autism Victoria) has developed a directory of services, an information line and autism advisors available for both parents and professionals. http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

- The ‘Raising Children Network’ is an interactive website designed to assist parents and professionals in finding and accessing available services and resources throughout Australia. http://raisingchildren.net.au/services_pathfinder/services_pathfinder.html

Federal Government:
http://australia.gov.au/directories/state-territory-and-local-government-directories
Victorian Government:
http://www.vic.gov.au/index.html
Local government
http://www.dpcd.vic.gov.au/localgovernment/find-your-local-council

# SECTION TWO

## OVERVIEW OF THE AUTISM SPECTRUM DISORDERS

Nearly 70 years ago, Dr. Leo Kanner introduced the term “autism”, derived from the Greek word ‘auto’ or ‘self’ (Kanner, 1943). Kanner described eleven children with previously unreported and distinctive patterns of symptoms including an inability to relate to people and situations, delayed and disordered language and repetitious behaviours with an obsessive desire for the maintenance of sameness. These core symptoms have remained central to the diagnosis of autism.

In 1980, the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-III) introduced the term Pervasive Developmental Disorders (PDDs) to describe a group of five conditions, including autism, which present in the first years of life and cause impairments in social interaction, communication, and play and behaviour. The current diagnostic manuals, both the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revised, of the American Psychiatric Association (DSM-IV-TR) (American Psychiatric Association, 2000) and the International Classification of Diseases and Related Health Problems (ICD-10) (World Health Organisation, 1992) continue to include five categories of PDDs: Autistic Disorder, Asperger’s Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Rett’s Disorder and Childhood Disintegrative Disorder.

Over recent years, there has been a move away from the term PDDs towards the term Autism Spectrum Disorders (ASDs). The term ASDs has been used not only to refer to a group of conditions which shared a ‘triad of impairments’, but also as a description of symptom severity, as a developmental concept and to describe a continuum of intellectual ability (Tonge, 2002; Wing, 1997). The term ASDs typically refers to a group of three conditions; Autistic Disorder, Asperger’s Disorder and PDD-NOS.

The American Psychiatric Association has recently proposed new diagnostic criteria for the fifth edition of the DSM (DSM-V) (APA, 2011) that will be published in 2013. The proposed changes include the replacement of the current five diagnostic subcategories to one broad category of ‘Autism Spectrum Disorder’. The earlier triad of symptoms (social, communication, and repetitive, restricted patterns of play and behaviour) is planned to be replaced by two categories: social communication, and restricted, repetitive patterns of behaviour, interests or activities. http://www.dsm5.org/Pages/Default.aspx . Changes are not currently proposed for ICD.

As this guide for CAMHS/CYMHS clinicians has been written prior to the publication of DSM-V, the term ASDs or ASD is used to refer collectively to individuals meeting criteria for Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder-Not Otherwise Specified as defined in the DSM-IV-TR (2000). When a distinction between these conditions is important, the specific term is used. Importantly, information about the proposed changes in the forthcoming DSM-V has also been included.

## Autistic disorder (Autism)

Autism is a lifelong neuro-developmental disorder which causes impairments in three core areas: social interaction, communication and restricted repetitive and stereotyped patterns of behaviour, interests and activities with onset prior to three years of age (DSM-IV-TR, APA, 2000).

i) Impaired social interaction

Qualitatively impaired social interactions were the focus of Kanner's original clinical description of children with autism (Kanner, 1943). A distinctive pattern of atypical social interactions remains a core feature of autism in DSM-IV-TR (APA, 2000) and the (ICD-10) (World Health Organisation, 1992) and is commonly viewed as the central and defining feature of autism (Lord et al., 2000).

Children with autism may display a flat facial affect and have fleeting or avoidant eye gaze. They rarely use eye contact to monitor or direct another's attention. As infants they may not use a social (protodeclarative) point to share interest and regulate interaction with others or engage in social imitation games such as waving bye-bye and playing peek-a-boo. Children with autism often have difficulty making friends with their peers; preferring solitary or parallel play. They may prefer the company of younger children, or those who are much older, rather than their own peer group. They rarely share their enjoyment, interest or successes with others or develop an age-appropriate empathy or ability to understand that other people have feelings.

Whilst all children with autism display social impairments, the nature of these deficits varies and modify as the child grows older. The child with autism may show an increased interest in peers and learn social skills, often in a rigid and inflexible manner. Adolescents with autism usually have to learn about social skills and personality development without the opportunity of peer group discussion and support available to typically developing adolescents (Howlin, 2005).

### ii) Impaired Communication

Qualitative impairments in both verbal and non-verbal communication skills are often the initial concerns for parents of children with autism. Parents express concerns about the slow onset of their child's speech, an absence of first words, an apparent slowing of development or the loss of previously acquired words. Approximately 50% of individuals with autism will not develop functional speech and follow-up studies have shown that most children with autism who do not have functional speech by the age of seven years will continue to have severely impaired communication (Howlin, 2005). Early language development and competence have been consistently associated with positive long-term outcomes for individuals with an ASD (Garfin & Lord, 1986; Howlin, 2005).

Children with autism usually have markedly delayed and disordered speech and do not compensate for this through the use of mime or gesture. In those children who do develop speech, the pattern of development is both unusual and idiosyncratic. The tone, pitch and modulation of the child's speech are often unusual; with a flat tone, an accent or extremes in volume. They sometimes develop neologisms (new words) or echolalia (repetition of words or phrases). Children with autism often have an impaired ability to initiate and maintain conversation and may interrupt or talk out of context rather than engaging in the 'to and fro' of conversation. Young children with autism may not develop spontaneous, imaginative, make-believe play.

Formal language assessment often reveals a difference between the child's expressive and receptive language skills. Their understanding of spoken language is often literal and they fail to comprehend underlying meaning and metaphor such as "stand up and be counted", or "pull your socks up". Those children with autism who develop speech usually have difficulty with pragmatic language skills. Howlin (1998) described this "failure to use communication for social purposes" as the most characteristic feature of the language deficit in autism.

### iii) Ritualistic and stereotyped patterns of behaviour, interests and activities

In his original account of autistic disorder, Kanner described children with stereotyped motor mannerisms, repetitive play and behaviours, non-functional routines and rituals and an obsessive desire for the maintenance of sameness (Kanner, 1943). These ritualistic and stereotyped patterns of behaviour, interests and activities remain a core feature of autism in the DSM-IV-TR (APA, 2000) and the ICD-10 (WHO, 1992).

Children with autism may display a preoccupation with stereotyped or restricted interests which they maintain to the exclusion of other activities. The child's encompassing preoccupations are unusual in intensity and interfere with other play and learning opportunities. Children with autism may have non-functional routines or rituals such as insisting on travelling the same route to kindergarten each day or repetitively lining up objects. The child may develop an intense attachment to favoured objects and display great distress if they are taken away or the patterns disrupted. There is often an associated resistance to change in the child's routine or environment with a preference for structure and sameness. Children with autism may have repetitive motor mannerisms such as hand flapping, finger twiddling, rocking or spinning. They may also be preoccupied with visually scrutinising the fine details of parts of objects such as the wheels on a toy train or the edges of furniture.

### CASE 1.

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*Campbell is a three year old boy who was recently diagnosed with Autistic disorder (Autism).Campbell was referred to the regional CAMHS assessment team by his paediatrician following concerns relating to his delayed language development, social difficulties and repetitive and challenging behaviours. Campbell's parents reported that his language was slow to develop and he was often was quite "intense" in his response to new situations. They were also worried about his very rigid and inflexible daily routine. They described him as "being in his own little world", preferring to be by himself rather than playing with other children. At the time of assessment, Campbell's language was delayed and disordered. He used jargon, repeated words and phrases (echolalia) and also had unusual intonation. Campbell was able to ask for things he wanted and repeat short sentences. However, back and forth conversational skills were yet to develop. He did not have any friendships with his peers and preferred to spend his time at child care by himself engaged in non-functional and repetitive play such as lining up his toy cars. He had poor use of eye contact and facial expression to interact with others.*

## Asperger’s disorder

Independent of Kanner, Austrian Psychiatrist Hans Asperger published a paper that reported on a group of children and adolescents with what he described as “autistic psychopathy” (Asperger, 1944). These school-aged boys had problems with social interaction, unusual and intense interests, behavioural problems and clumsiness, but no significant delays in cognitive or language development. Since Asperger’s paper was translated from German to English by Uta Frith in 1991 there has been increasing interest and debate over whether Asperger’s disorder is a separate disorder to Autism. Whilst many publications have tried to delineate the boundaries, if any, between Autism and Asperger’s disorder, the relationship between the two disorders has remained unresolved (Gillberg & Gillberg, 1989; Klin, McPartland & Volkmar, 2005; Rutter, 1999; Szatmari, Bryson, Boyle, Streiner & Duku, 1989; Wing, 1981; Woodbury-Smith & Volkmar, 2009; Yu, Cheung, Chua & McAlonan, 2011). Despite the differences that can be seen when looking at the original cases described by both Kanner and Asperger, there is continuing confusion over the diagnostic criteria for Asperger’s disorder, particularly as subsequent accounts and case studies have not necessarily adhered to the criteria suggested by Asperger himself.

DSM-IV-TR (2000) provides criteria for a differential diagnosis of Asperger’s and Autistic disorder based on exclusionary criteria, that for Asperger’s disorder there is (i) no clinically significant general delay in the acquisition of language, and (ii) no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood. The two core areas of impairment in Asperger’s disorder are impaired social interaction and restricted repetitive & stereotyped patterns of behaviour, interests and activities. The disorder must cause clinically significant impairment in social, occupational, or other areas of functioning, and finally, the child must not meet criteria for another PDD or schizophrenia (DSM-IV-TR, APA, 2000).

Neither ICD-10 (1992) nor DSM-IV-TR (2000) stipulates the criteria for age of onset for Asperger’s disorder as they do for Autistic disorder. However, in his original paper, Asperger (1944) described children as having difficulties by the age of two. Because children with Asperger’s disorder do not have delayed language or cognitive development, it tends to be diagnosed later than autism. It is more usual for parents to become worried about their child’s behaviour and social development from about four years or older (McPartland & Klin, 2006) when the child attends an early childhood program where there are more demands for social interaction.

**CASE 2.**

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*Daniel's parents had always felt that their son seemed to be "quirky" and different to their other children. Although he learned to walk and talk at the expected times he had difficulty using gestures, such as pointing to share his interest. At kindergarten, he showed interest in playing with other children but was bossy and controlling. He would have a tantrum if his routine was changed and repetitively sorted his toys according to colour and size. He spent most of his day learning about dinosaurs and sharks and talked about them without any regard for the listeners' interest.*

*At the age of 15, Daniel was referred to the CAMHS ASD assessment team by his parents who had become increasingly concerned about how he would cope with life after secondary school. Daniel was diagnosed with Asperger's disorder. Although his IQ was in the average range, he struggled to cope with the demands of secondary school. Daniel had established a small friendship group, but had little interest in seeing his friends outside of school. He preferred to spend time alone. He often made interesting or unusual comments, however jokes and humour were difficult for him to understand. Cooking became Daniel's favourite interest. He collected recipe books and talked about recipes without any regard for the listeners' interest. He found it difficult to cope in noisy social environments. Daniel had no interest in sport, and his coordination and handwriting were poor.*

## Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS)

PDD-NOS, sometimes described as atypical autism (WHO, 1992) is a diagnosis given to individuals with a pervasive developmental disorder whose clinical symptoms are not better described by one of the other categories (Towbin, 2005). This may be because of the age of onset, or because the individual does not have the key symptoms of other PDDs Because of the lack of clear criteria, this diagnosis is often misunderstood and therefore is sometimes given when there is insufficient information, when the developmental history is unreliable, to describe a 'milder' form of autism or as a provisional diagnosis.

DSM-IV-TR describes PDD-NOS as a severe impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interests and activities (APA, 2000).

**CASE 3.**

*Jerome was referred to the CYMHS ASD assessment team at 14 years of age by a paediatrician following ongoing concerns about his poor social interaction and repetitive and restricted interest in cars and trains. As a younger child, Jerome's parents were concerned about his difficulties in relating to people. Jerome's social difficulties became more apparent during his upper primary school years when tantrums and aggressive outbursts escalated at home and school. Jerome's mother reported that his language developed a little slower than her other children, but he was speaking in sentences by age three years. There was no reported use of jargon or echolalia.*

*At 14 years of age, Jerome was found to have poor use of non-verbal communication such as facial expression and gesture used to socially interact. He had ongoing difficult in understanding other people's emotions. Jerome had no close friends and was isolated at school. He continued to have an encompassing preoccupation with cars and trains and had a range of non-functional daily routines and rituals.*

## Intellectual ability and cognition

Intellectual disability, medical conditions, mental health problems and other associated characteristics must also be considered because of their frequent co-occurrence with ASDs (Amiet et al., 2008; Bradley et al., 2004; Fombonne, 2005; Gadow et al., 2004; Gillberg & Billstedt, 2000; Rutter, 1983; Sverd, 2003; Tuchman & Rapin, 2002; Tonge & Einfeld, 2003; Volkmar & Klin, 2005).

### i) Intellectual ability

The majority of children with autism have an intellectual disability (ID) (Volkmar & Klin, 2005) with approximately 20-30% scoring within the normal range of intelligence, 30% score within the mild-moderate range of intellectual disability and about 40% in the severe to profound range (Fombonne, 2005). Whilst children with autism can be difficult to assess using standardised cognitive assessments, it has been found that if appropriate tests are used, the results are valid and reliable (Clark & Rutter, 1979) and are stable over time (Howlin, 2005). Individuals with autism who have overall cognitive abilities in the normal range are often referred to as having 'High

Functioning Autism' (HFA). IQ scores on standardised tests of intelligence of children with ASDs typically show an unusual and distinctive pattern of performance with stronger rote memory skills and deficits in verbal sequencing and abstraction skills.

Unusual or exceptional cognitive skills were initially described by Kanner (1943) and Asperger (1944). A recent study (Howlin, Goode, Hutton & Rutter., 2009) showed that approximately one third of individuals with autism had either a savant skill (e.g. music, math) based on parental report or an exceptional cognitive skill. Howlin et al., (2009) also found that no individual with a non-verbal IQ below 50 met the criteria for a savant skill suggesting that the much-used term of ‘‘Idiot Savant’’ is misleading.

### ii) Cognition

Executive function, theory of mind and central coherence are three key cognitive theories that have been researched to understand the link between brain and behaviour in individuals with an ASD.

Executive function is commonly used as an umbrella term which includes cognitive processes of planning, inhibition and flexibility, organisational skills, shifting set, self-monitoring and working memory (Hill, 2004; Ozonoff, South & Provencal, 2007). Executive functions have been reported in the literature for over two decades for individuals with autism across all ages and intellectual abilities. Studies have identified problems in individuals with an ASD with mental flexibility, demonstrated by stereotyped behaviour, perseveration and problems in regulating motor acts (Hill, 2004; Hill & Russell, 2002; Hughes & Graham., 2002; Rinehart, Bradshaw, Brereton, & Tonge, 2002; Rinehart, Bradshaw, Moss, Brereton & Tonge, 2000; Shu, Lung, Tien, & Chen, 2001). Other studies have found that children and adults with autism have impaired planning abilities and cognitive flexibility compared to typically developing individuals and those with other clinical disorders such as ADHD and Tourette’s syndrome (Geurts, Verté, Oosterlaan, Roeyers, & Sergeant; 2004; Ozonoff & Jensen, 1999).

Theory of mind is involves the ability to attribute or infer beliefs, intentions, imagination, desires, and emotions to oneself and others and to understand that others have beliefs, desires and intentions that are different from one's own. Theory of mind is considered to be a cognitive construct that develops during childhood (Brune & Brune-Cohrs, 2006) that includes following another's gaze in infancy, engaging in pretend play in the pre-school years, to comprehending jokes, irony and metaphor in later years. Researchers have found impairments in theory of mind in individuals with an ASD (Baron-Cohen, Joliffe, Mortimore, & Robertson, 1997; Happé, 1995; Yirmiya, Shaked, & Solomonica-Levi, 1998) with recent research focusing on the functional relations between theory of mind and other cognitive abilities such as executive function (Ahmed & Miller, 2011; Fisher & Happé, 2005; Joseph & Tager-Flusberg, 2004).

Kanner's original paper described children who had difficulty deriving overall meaning from parts and details (Kanner, 1943). Four decades later, Frith (1989, as cited in Happé & Frith, 2006) described weak central coherence in individuals with autism who focus on detail rather than the whole. Frith (1991) described the core attribute common to all people with autism as "the inability to draw together information so as to derive coherent and meaningful ideas" (p. 186). The theory of weak central coherence has been modified through more recent research which indicates a relationship between central coherence and other cognitive abilities such as theory of mind (Baron-Cohen & Hammer, 1997; Happé & Frith, 2006; Pellicano, 2010; Pellicano, Durkin & Maley, 2006).

## Medical and mental health

### i) Medical conditions

Fragile X Syndrome and Tuberous Sclerosis are recognised as being associated with autism in a small proportion of individuals (Volkmar & Klin, 2005). Despite previous reports, recent surveys do not suggest any particular association between autism and cerebral palsy, phenylketonuria, congenital rubella or Down syndrome (Fombonne, 2005). The association between PDDs and epilepsy has been consistently reported with prevalence rates of epilepsy in those with autism varying from 5% - 40% compared to the general population of .5% - 1% (Amiet et al., 2008). Amiet et al. (2008) reported that the risk for epilepsy in autism is related to intellectual disability, with epilepsy being more prevalent in those with autism and severe intellectual disability. The risk for epilepsy in females with autism was also found to be significantly higher (Amiet et al., 2008). Peak periods of seizure onset are reported to be in early childhood and adolescence (Tuchman & Rapin, 2002). Larsson et al. (2005) also reported an increased risk of autism in children who have traumatic births.

### ii) Mental health

Many studies have found high levels of emotional and behavioural disturbance in individuals with autism (Bradley et al., 2004; Lainhart & Folstein, 1994; Smalley, McCracken & Tanguay, 1995; Steinhausen & Metzke, 2004). Mental health problems in toddlers, children and adolescents with ASDs has been found to contribute to maternal stress and parental mental health problems (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hastings et al., 2005; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Tonge & Einfeld, 2003).

Hutton, Goode, Murphy, LeCouteur & Rutter (2008) found in their study that approximately one-fifth of individuals with autism developed a new psychiatric disorder by adult life. All types of psychiatric disorders occur in individuals with an ASD (Ghaziuddin, 2005; Hutton et al., 2008) and they present with more psychiatric symptoms or disorders than the general population (Bradley et al., 2004; Bradley et al., 2007; Gadow et al., 2004; Gillberg & Billstedt, 2000; Leyfer et al., 2006; Simonoff et al., 2008; Tonge & Einfeld, 2003). Psychiatric disorders can also be multiple in those with an ASD (Simonoff et al., 2008). These primarily include anxiety disorders (Fombonne, 1992; Gillot, Furniss & Walter, 2001; Nick, Szatmari, Bryson, Streiner & Wilson, 2000; Simonoff et al., 2008) depression and other mood disorders (Bradley et al., 2004; Brereton et al., 2006; Lainhart & Folstein, 1994; Ghaziuddin, Ghaziuddin & Greden, 2002; Tonge & Einfeld, 2003) and symptoms of ADHD (Goldstein & Schwebach, 2004; Nick et al., 2000; Loveland & Tunali-Kotoski, 1997; Rinehart & Tonge, 2007; Simonoff et. al., 2008).

Whilst comorbid psychiatric symptoms in those with an ASD is now well described in the literature, infrequent identification and diagnosis may be due to diagnostic overshadowing in which the psychiatric symptoms are attributed to the ASD or ID (Simonoff et al., 2008). The impact of comorbid mental health problems on the long-term adjustment, wellbeing and outcome for individuals with an ASD is still unclear. There is evidence of increased genetic vulnerability to a range of mental health problems, such as the association with familial depression (Bolton, Pickles, Murphy & Rutter, 1998; Piven & Palmer, 1999), bipolar disorder (DeLong & Dwyer, 1988) and ADHD (Goldstein & Schwebach, 2004; Reierson, Constantino, Volk & Todd, 2007).

## Associated characteristics

Sensory disturbance, sleep problems, fussy eating, and motor impairments are often associated with ASDs, but may also occur in children with other developmental problems and are not specific to children with an ASD.

### i) Sensory disturbance

Sensory problems are often associated with ASDs, but may also occur in children with other developmental problems and are not specific to children with an ASD. Autobiographical accounts from adults with High Functioning Autism have been published and report unusual responses to sensory stimuli (Grandin, 1995). Sensory problems are described as contributing to high levels of distress, fear and anxiety, which disrupt daily life and social functioning, but also as a source of pleasure and safety (O'Neill & Jones, 1997). Research studies on sensory problems for individuals with autism are limited compared to studies of other aspects of development and often suffer from methodological limitations. However, empirical studies suggest that sensory problems are present in most children with autism and they manifest very early in development (Baranek, 2002). The criteria for the proposed DSM-V includes a new category of hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (APA, 2011)

### ii) Sleep problems

Reports of sleep problems in children with an ASD range from 40% - 80% compared to 30% for typically developing children (Goodlin-Jones et al., 2009). Parents of children with an ASD commonly report problems with their child going to bed, falling asleep and waking frequently, which are associated with disruptive daytime behaviour and increased family stress (Richdale, Francis, Gavidia-Payne & Cotton, 2000).

### iii) Fussy eating

While fussy eating can be a normal part of early childhood development, children with autism exhibit more eating and meal-time problems and eat fewer foods from each food group (fruits, dairy, vegetables, proteins, starches), than typically developing children (Schreck et al., 2004). Whilst there have been numerous reports on fussy eating in children with an ASD, few have provided systematic objective evaluations of either the prevalence or nature of their feeding problems. However, the range of concerns described by parents and reported in the literature generally relate to food/liquid selectivity based on presentation or type, food refusal, and concerns about unusual mealtime behaviours, such as sniffing or inspecting foods, gorging, hording or gagging. When eating problems persist and parents are concerned about their child's nutritional intake, a consultation with a medical practitioner (GP) is advised. Dieticians working in Early Childhood Intervention Services or in Community Health Centres can also be helpful.

iv) Motor impairment

Recent research is investigating whether neuro-developmental problems involving motor dysfunction are an additional core behavioural symptom of ASDs (Ming, Brimacombe & Wagner, 2007). The literature describes delayed motor milestones, clumsiness, poor co-ordination, impaired postural control, awkward gait and motor planning problems in children with an ASD (Ghaziuddin, Butler, Tsai & Ghaziuddin, 1994; Green et al., 2002; Ming, Brimacombe & Wagner, 2007; Mostofsky, Burgess, & Gidley Larson, 2007; Rinehart et al., 2001; Rinehart et al., 2006). Van Waelvelde (2010) has also reported consistency of poor motor performance over time in children with autism.

## Prevalence

There have been an increasing number of epidemiological surveys of PDDs in recent years, largely due to concerns that the prevalence of these disorders is increasing. Contributing to these concerns is the confusion between the term prevalence (cases with the disorder at a specified time) and incidence (the rate of new cases of the disorder within a specified period of time) (Volkmar et al., 2004). Other factors that contribute to confusion and interpretation of increased prevalence rates include changes in diagnostic practice, increased awareness of ASDs, earlier diagnosis, study design, case ascertainment and diagnostic substitution (Volkmar et al., 2004). Recent comparison between 34 surveys reporting data on the prevalence of PDDs estimates that the prevalence of autistic disorder is 13 per 10,000, Asperger's disorder is approximately 3 per 10,000, PDD-NOS is 20 per 10,000 and about 2 per 100,000 for childhood disintegrative disorder (Fombonne, 2005). Rett's Disorder is reported at 1 per 10,000 (Korinetz et al., 1997). An Australian study found that ASDs affect 1 per 160 Australian children aged between 6 and 12 years of age (Williams, McDermott, Ridley, Glasson, & Wray, 2008).

Siblings of individuals with an ASD are known to have a substantially elevated risk of also having a diagnosis, with evidence of cases of autistic disorder among siblings ranging from 2-6% (Newschaffer, Fallin & Lee, 2002). Whilst early epidemiological surveys suggested a correlation between social class and autism, more recent studies find PDDs across all social classes with similar frequencies (Fombonne, 2005). Clinical and epidemiological surveys report a higher incidence of autism in boys than in girls with ratios of approximately 4:1 (Volkmar et al., 2004).

## Causes

Causation theories have changed markedly since Kanner and Asperger first described these disorders. During the 1940s and 1950s the psychogenic theory of causation predominated, blaming inadequate parenting. More recently, studies have investigated environmental and genetic factors.

Autism is known to be among the most heritable of neuropsychiatric disorders (Bailey et al., 1995; Steffenberg et al., 1989). Evidence supporting a significant genetic contribution to ASDs has been increasing over the past few decades, but the variants causing, or increasing, the risk for these disorders is not yet understood (Gupta & State, 2007). The patterns of genetic inheritance are complex and no gene has been unequivocally identified to date (Yang & Gill, 2007). Recent research has also begun to investigate the presence of non-inheritable risk factors, but due to the evidence on heritability it appears that environmental factors may also involve some genetic susceptibility (Newschaffer et al., 2002). A recent study on twin pairs with autism suggests that environmental factors common to twins explain approximately 55% of the liability to autism and conclude that genetic factors play an important role, but with substantially lower magnitude, than estimates from prior twin studies of autism (Hallmayer et al., 2011). Over the past decade there has been considerable discussion, publicity and research concerning the hypotheses that there is a link between autism and immunization. In particular, the measles component of the measles-mumps-rubella vaccine was implicated, and the amount of thimerosal contained in most other childhood vaccines (Wakefield et al., 1998). Comprehensive epidemiologic, biological, molecular and animal model studies have provided no evidence to support a link between measles-mumps-rubella vaccination and ASDs (DeStefano, Price, & Weintraub, 2013; Fombonne, 2008; Honda, Shimizu, & Rutter, 2005; Peltola et al., 1998; Smeeth et al., 2004).

There has been some evidence to suggest that advanced paternal age, advanced maternal age, growth restriction and newborn hypoxia are associated with an increased risk of ASDs (Kolevzon, Gross & Reichenberg, 2007; Lundström et al., 2010). A number of studies have identified an association between pre-, peri- and post-natal factors and autism (Gardener, Spiegelman, & Buka, 2011; Juul-Dam, Couchesne, 2001; Kolevzon, et al., 2007).

# SECTION THREE

## Early Childhood (The pre-school years)

## Identification & referral (Early childhood)

There are several important approaches to the identification of child developmental problems, including ASDs, which are not mutually exclusive. These include valuing and responding to parental concerns, surveillance or monitoring procedures and the use of valid and reliable screening instruments. The monitoring of development should be a parent-professional activity which promotes timely referral to education, assessment and support services.

### Valuing and responding to parental concerns

Parents can be reliable observers of their child's behaviour and development and when they have concerns, there is considerable likelihood that the child will have problems (Glascoe, 2000). This is also the case for parents of children with an ASD. However, lack of parental concern may not mean that the child's behaviour and development is normal as parental recall of developmental milestones may be biased, particularly if a significant delay is not present. Recent studies have found no differences in the accuracy of parental concerns on the basis of socio-economic status, number of children in the family, birth order, participation in day-care, parenting experience, or the parent's exposure to other family members with a disability (Glascoe, 2011). Studies indicate that most parents want clarity about their child's developmental or behavioural problems and their stress was at its peak before, and when trying to obtain, a diagnosis (Konstantareas, 1989).

Recent studies agree with earlier research which found that most parents of children with autism notice problems in their child's development and behaviour very early. DeGiacomo & Fombonne, (1998) reported that approximately 30% of parents of children later diagnosed with autism were concerned about their infant's development before they turned one, and 80% by the age of two. Howlin & Asgharian (1999) also found that parents of children with autism reported first recognition of developmental problems before two years of age. Chawarska et al. (2007) supported these findings and found that parents of children diagnosed with autism or PDD-NOS reported problems at a mean age of 14-15 months. Research has consistently identified that parents first noticed, and were most commonly concerned about their child's delayed speech and language development (DeGiacomo & Fombonne, 1998; Chawarska et al., 2007).

These early concerns are not shared by the parents of children with Asperger's disorder, as their children develop age appropriate language and cognitive skills. Therefore, children with Asperger's disorder are typically not detected until they become involved in the more complex social environment of pre-school or school. Diagnosis of Asperger's disorder is often not made until after the child is four years of age, or older (McPartland & Klin, 2006). Despite later diagnosis, parents of children diagnosed with Asperger's disorder retrospectively report concerns about their child's development and behaviour before the age of three, or even earlier (Chakrabarti & Fombonne, 2005).

Although many parents are concerned about their child's development in their first years, formal diagnoses is often delayed (Howlin & Moore, 1997; Siegel, Pliner, Eschler & Elliot, 1988). Although waiting lists for assessment may contribute to this delay, some parents comment that professional response to their concerns has been inappropriate reassurance ("*Boys are usually a bit slow to start talking. Let's give him another six months and see how he's getting on then").* Any parental concern about a child's development and/or behaviour should be acknowledged and discussed fully, and appropriate referral made.

## Monitoring or Surveillance

Developmental monitoring or surveillance requires the ongoing and systematic collection of information and review of child and family over time by an integrated service system (Dworkin, 2000; Lamont-Herps and Robson, 2001; Oberklaid et al., 2002, Oberklaid, 2011). It includes eliciting parent concerns, observation and examination over time, informal observations, and the administration of reliable tests and procedures. Developmental surveillance aims not only to detect delays early, but also identify and intervene into risk factors for child development (e.g. siblings of individuals with an ASD). Surveillance, or monitoring, of child health and development should be integral to primary care clinical practice (Oberklaid, 2011). Concerns raised through developmental surveillance should lead to screening or referral for further assessment.

In Victoria, the Parents' Evaluation of Developmental Status (PEDS) (Glascoe, 2003) is increasingly being used by GPs, maternal and child health nurses and early childhood educators to use their regular encounters with young children as an opportunity to elicit developmental information and concerns from their parent/s. The use of the PEDS actively includes parents in surveillance, making surveillance a parent-professional activity. This active participation and careful eliciting of parental concerns have been shown to fairly accurately identify developmental, language and behavioural problems (Glascoe, 2000).

### i) Parents' Evaluation of Developmental Status (PEDS)

PEDS is a 10-item questionnaire suitable for use between birth and 8 years of age. Parental responses to the questions are scored using an accompanying scoresheet and categorised into a number of action pathways. It can be completed before or during a consultation and takes only a few minutes to complete and score. The use of the PEDS as a screening test has been validated against standard psychometric tests in a series of studies in the USA (sensitivity and specificity between 70-80%). The PEDS is a family-centred approach to addressing concerns.

http://www.rch.org.au/ccch/resources.cfm?doc_id=10963

### ii) Maternal & Child Health ages and stages surveillance protocols

The Maternal and Child Health (MCH) Key Ages and Stages revised framework was rolled out throughout Victoria in 2009. The objectives of this framework were to realign the Universal MCH Service Key Ages and Stages activity framework in accordance with current evidence, to strengthen the clinical role of the Maternal and Child Health Nurses, and to maintain the reputation of the Universal Victorian MCH service as an international leader. This framework includes a move away from the pass/fail concept of tests at single time-points towards a more flexible, longitudinal process of surveillance.

The MCH surveillance protocols include:

- PEDS as a primary developmental screening tool
- Brigance Screen as a secondary developmental screen
- Consistent, evidence based and relevant promotion of health and development brochures, activities and messages
- Consistent, evidence based and relevant interventions (e.g. SIDS risk assessment, Quit smoking intervention, screening of maternal health and the presence of family violence, surveillance of developmental problems including ASDs)

This revised framework provides a way to monitor the healthy growth and development of a child through an active partnership of parents and MCH nurses. The parents bring observations and experience of their child and the MCH nurse ensures that the full range of a child's development (physical, cognitive, and social-emotional) is monitored at each visit. Through observation, measurement, surveillance, screening, and listening and sharing with parents, the nurse evaluates a child's healthy development. Each of the MCH Key Ages and Stages consultations (4 month, 8 month, 12 month, 18 month, 2 years and 3.5 years) provides an opportunity for parents to discuss any concerns about their child.

In 2011, Victoria's MCH branch, in conjunction with Monash University's Autism Consultation and Training strategy (ACT-NOW), provided professional development and resources to MCH nurses throughout the state on the surveillance and early signs of ASDs. A standard referral form was developed to allow the MCHN to alert medical practitioners and other relevant professionals of their concerns PEDS and Brigance results are attached to the referral form to provide additional information about the child's behaviour and development.

- MCH Developmental referral form:

http://www.eduweb.vic.gov.au/edulibrary/public/earlychildhood/mch/autism_referral_form.pdf

## Screening

Screening involves the use of specific tests or examinations to identify those people in a population who are likely to have a particular condition or disorder (Baird et al., 2001; Oberklaid at al., 2002). Screens are not diagnostic, but sort out those who are likely to have the condition from those who are likely not to. Screening instruments can provide valuable information about a child's development and behaviour and can provide a structure for parents and professionals to talk about their understanding of the child in different settings. This is an important 'first step' in informing parents and professionals of the need for referral for further assessment.

Best practice guidelines indicate that autism screens are particularly important for 'at-risk' groups including:

- ✓ Siblings of children with an ASD
- ✓ Children with a developmental delay
- ✓ Children with emotional and behavioural problems
- ✓ Children with genetic syndromes or other developmental problems

Valid and reliable screening instruments currently used in Victoria include:

i) The Checklist for Autism in Toddlers

The Checklist for Autism in Toddlers (ChAT) was developed as a primary screen for children at 18 months of age (Baron-Cohen et al., 1992). The ChAT has nine questions that are answered by parents and a further five observation items made by a general practitioner or primary health care worker. The original study focussed on impairments in early social communication; in particular, joint attention and pretend play. In a later, large population study of 16,000 children, the authors concluded that consistent failure of three key ChAT items (protodeclarative pointing, pretend play and gaze monitoring) at 18 months carried an 83.3% risk of autism (Baron-Cohen et al., 2000).

http://www.med.monash.edu.au/spppm/research/devpsych/actnow/factsheet10.html\

### ii) The Modified Checklist for Autism in Toddlers

The Modified Checklist for Autism in Toddlers (M-CHAT) is an adaptation of the ChAT, It is a twenty-three item checklist completed by parents of toddlers between the ages 16 to 30 months that does not require clinician observation (Robins et al., 2001). There are six critical items that relate to joint attention, social relatedness and communication which as a group discriminate children with autism from other children.

http://www.firstsigns.org/

### iii) The Developmental Behaviour Checklist

The Developmental Behaviour Checklist (DBC) is a parent-completed, reliable and valid autism screening tool for at-risk populations (Einfeld & Tonge, 2002). The DBC Autism Screening Algorithm (DBC-ASA) is a twenty-nine item scale used for discriminating children and young people (aged 4-18) with autism (Brereton et al., 2002). The DBC Early Screen has more recently been developed as a screening tool for autism in children with developmental delay aged 18-48 months (Gray & Tonge, 2005). It provides a simple and inexpensive method of screening at risk populations of preschool children with developmental delay for autism. The DBC-P (parent) has been translated into other languages including Arabic, Chinese, Croatian, Dutch, Finnish, French, German, Greek, Hindi, Italian, Japanese, Malay, Norwegian, Portuguese, Portuguese (Brazil), Spanish, Swedish, Turkish and Vietnamese.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

## The early signs of autism

The symptoms of autism begin in the first two years of life, but there is limited evidence regarding the timing of onset and the nature and severity of the core symptoms (Chawarska et al., 2007). A number of international best practice guidelines and reports have outlined some of the early indicators of autism that are important for health practitioners to recognise and respond to. (LeCouteur, 2003; Perry & Condillac, 2003; Osbourne & Scott, 2004; Filipek et al., 2000; Californian Department of Developmental Services, 2002). These 'red-flags' should be known to all primary care professionals, including maternal and child health nurses, GPs, early childhood carers/educators as signs which indicate immediate referral. In Victoria, the five 'red flags' are increasingly being recognised by universal services at primary indicators for referral.

### The 'red flags' for autism

- Does not babble or coo by 12 months of age
- Does not gesture (point, wave etc.) by 12 months of age
- Does not say single words by 16 months of age
- Does not say two-word phrases on his or her own (rather than just repeating what someone says to him or her) by 24 months of age
- Has any loss of any language or social skill at any age

(Fillipek et al., 2000)

Recent research indicates that loss of previously acquired skills, or regression, is reported in 20% - 33% of cases and can include loss of words, vocalisations, non-verbal communication, social dyadic interaction skills, imitation or pretend play (Chawarska et al, 2007). The common time for change is reported as between 15-19 months (Charman & Baird, 2002). The apparent onset of regressive autism is distressing to parents. The pattern of symptoms has led to suspicions that postnatal environmental factors such as the MMR vaccine trigger autism. Although controversy has escalated since the earliest reports of a possible link began to surface in the 1980s, no casual link has been found (Demicheli et al., 2005; Honda, Shimizu & Rutter, 2005; Madsen et al, 2002).

## EARLY INDICATORS OF AUTISM

**Social interaction**

Not pointing to share attention and interest
Difficulty in coordinating, monitoring and shifting eye gaze with others
Not seeking or offering comfort and affection
Not using an anticipatory posture – raising arms to be picked up
Lack of attention to voices or name being called
Preference to be alone
No social smile
Limited response to, and use of facial expressions

**Communication**

Delayed infant babble and vocalization
Delayed onset of speech
Echolalia – repeating words
Poor imitation skills ( e.g. waving bye-bye)
Using other's body as a tool
Delayed pretend play
Loss of previously acquired words
Poor understanding of speech and gestures

**Play & Behaviour**

Repetitive hand, finger and body mannerisms
Less object exploration and spontaneous play
Unusual or repetitive preoccupations
Unusual or repetitive attachment to objects
Lack of social imitative play
Unusual sensory interest or response

Brereton & Bull (2011)

## Referral

Referral and support should take place as soon as there is a concern about a child’s development or behaviour. It is not necessary to wait for a diagnosis of an ASD. In Victoria there are a number of referral pathways when parents and professionals are concerned about a child’s development and behaviour. This makes it confusing for parents and professionals alike. When concerns are raised, a referral with supporting documentation can be made by parent/s or professionals to one or several of the following services.

i) Primary health practitioner (Maternal and Child Health Nurse, General Practitioner)

Parental concerns about a child’s development or behaviour are often discussed with a primary health practitioner such as a Maternal and Child Health Nurse or General Practitioner (GP).

The Maternal and Child Health Nurse

The Maternal and Child Health Nurse (MCHN) can provide ongoing surveillance (PEDS) and developmental screening (Brigance) through the child’s early years (see above). When concerns about a child’s behaviour and developmental are determined through the surveillance protocols, the MCHN will make a referral to a GP and/or an early childhood intervention service and/or an allied health practitioner. MCHN cannot make a direct referral to a specialist medical practitioner such as a paediatrician or child psychiatrist.

General Practitioner

Young children are often referred to the local GP when there is a concern about behaviour and development. GPs can conduct an initial medical assessment including vision and hearing, and use a screening instrument to guide referral where appropriate. Referral may then be made to a medical specialist such as a Paediatrician or Child Psychiatrist, to an allied health practitioner, or to an ASDs assessment service such as CAMHS/CYMHS. GPs can provide a referral to specialist medical practitioners and can also complete the necessary documentation for access to Medicare rebates for allied health services, assessment services and support through Centrelink. GPs also have a critical role in the ongoing monitoring of health issues over the lifespan for those children diagnosed with an ASD.

Referral to a GP should include relevant supporting documentation and an indication of specific concerns and desired outcome (e.g. referral to paediatrician). The referrer should follow up with the family to be sure that the referral has progressed.

Information for GPs on the ‘red flags’ of autism is available for GPs on podcast:

http://www.racgp.org.au/Content/NavigationMenu/Publcations/AustralianFamilyPhys/AFPPodcasts/podcast201109.htm

ii) Early Childhood Intervention Services ph. 1300363514

Early Childhood Intervention Services (ECIS) support children with a disability or developmental delay from birth to school entry and their families. ECIS provides special education, therapy, counselling, service planning and coordination, and assistance and support to access services such as kindergarten and child care. These services are funded through the Department of Education and Early Childhood Development (DEECD) and provided by Specialist Children's Services (SCS) teams and Early Childhood Intervention agencies (e.g. SCOPE, Yooralla, Noah’s Ark)

In Victoria, referrals for ECIS are managed through a central intake service which works with the family to identify concerns, to plan next steps and to make a referral to an ECIS agency and other relevant services for ongoing support and intervention.

http://www.education.vic.gov.au/ecsmanagement/intervention/default.htm

iii) Community Health Services

Community Health Services (CHS) provide a range of programs that aim to promote health, wellbeing and independence of children and families. CHS provide a range of paediatric services that include allied health (speech pathology, physiotherapy, occupational therapy, dietician…) and family services (counselling, family support, psychology…)

http://www.health.vic.gov.au/pch/

iv) Allied Health Practitioners

Referral may also be made to an allied health practitioner such as a Speech Pathologist, Psychologist, Special Education Teacher or Occupational Therapist for assessment and intervention. Therapists and specialist teachers typically work within a local community health centre or through a private practice. Initial assessment from an allied health practitioner may also later be used to contribute to a diagnosis.

Professional organisations have online lists of registered therapists

Australian Psychological Society

http://www.psychology.org.au/findapsychologist/

Occupational Therapy Australia

http://www.otaus.com.au/findanot

Speech Pathology Australia

http://www.speechpathologyaustralia.org.au/about-spa/find-a-speech-pathologist

**Other referral information**

- The 'Raising Children Network' website has an interactive Autism Service Pathfinder to assist parents and professionals in finding and accessing available services and resources throughout Australia. The pathfinder begins with parent and professional first concerns about a child's behaviour and development.

  http://raisingchildren.net.au/services_pathfinder/services_pathfinder.html

- Amaze (Autism Victoria) has a directory of services available through the information line.

  http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

- The Association for Children with a Disability (ACD) has a comprehensive booklet titled 'Through the Maze' which outlines services and resources in Victoria for parent and children 0-18 years (translations available in community languages)

  http://www.acd.org.au/information/ttmb.htm

# Assessment & Diagnosis (Early childhood)

## ASD assessment guidelines

Early and accurate diagnosis can provide an understanding of the child's behaviour and development, guidance for evidence based early childhood interventions,  a response to the needs of siblings who are 'at risk' of poor developmental outcome and access to services and support for the child and family.

Diagnosing ASDs is challenging for professionals as there is not a simple diagnostic test that provides a definitive answer. Because the aetiology of ASDs is largely unknown, diagnosis relies on diagnostic criteria being matched with behavioural description, observation of behaviour patterns and the child's course of development. A comprehensive multi-disciplinary assessment should always include expert clinical judgment combined with a range of valid and reliable standardized instruments. Currently, the international classification standard for establishing a diagnosis of autism and other pervasive developmental disorders is outlined in both the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revised, of the American Psychiatric Association (DSM-IV-TR) (APA, 2000) and the International Classification of Diseases and Related Health Problems (ICD-10) (WHO 1992). The revision of the DSM is due to be published in May 2013.

Studies have indicated for some years now that accurate diagnosis of autism can be made at 24-30 months (Gillberg et al., 1990; Lord 1995; Moore & Goodson, 2003; Stone et al. 1999). However, it is more difficult for those children who also have a significant developmental delay, or those who are higher functioning (Cox, 1999). Assessment and diagnosis of very young children presents with particular challenges. Young children with an ASD present differently depending on their current symptoms which change over time, their language and cognitive ability. Co-morbid conditions may 'over-shadow' the diagnosis of an ASD, so that parents and professionals may attribute all of the child's presenting behaviour to a pre-existing diagnosis such as ADHD, rather than as an additional condition. Other diagnoses also need to be considered. Common differential diagnosis and/or co-morbid conditions in the early childhood years include hearing impairment, developmental delay, language disorders, attention deficit disorders, behavioural disorders, and attachment disorder.

Thorough assessment by professionals with experience and expertise in ASDs is required to understand coexisting and alternative conditions (New Zealand Ministry of Health and Education, 2008).

ASDs are complex disorders and undertaking an ASD assessment requires a rigorous, comprehensive and systematic approach. Professionals involved in ASD assessments require training, experience and supervision. In Victoria, ASDs assessment guidelines have been developed by Autism Victoria (2009). The 'Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders' provide a definition of ASDs, outline assessment standards and guidelines, and list eligibility criteria for government funded services. The guidelines advocate a multi-disciplinary approach to assessment using DSM-IV-TR criteria.

- Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders'

http://www.amaze.org.au/uploads/2010/11/ASD-Diagnosis-Assessment-Guidelines-Victoria.pdf

## The diagnostic process

Whilst Autism Victoria's (2009) diagnostic process guidelines provide standards, the process of assessment varies from one service or clinic to another and, as such, children and their families have different experiences. International studies have shown that parents are sometimes dissatisfied with the assessment process, and also with how the diagnosis was communicated to them (Chamak, Bonniau, Oudaya & Ehrenberg, 2011; Goin-Kochel et al., 2006; Howlin & Moore, 1997). The time of diagnosis is a critical time when parents are told their child has a lifelong disability . It is an experience that parents don't forget. It is suggested that the manner in which professionals discuss the diagnosis with parents may affect the parents ability to cope and adapt, as well as their perception and subsequent care of their child (Silove, 2011).

Howlin and Moore (1997) surveyed 1,295 parents of children aged 2-49 years in the UK to investigate their views of the diagnostic process. Results indicated that parents were frustrated by lengthy delays, with parental satisfaction with the diagnostic process reported to be affected by the length of time they waited before receiving a final diagnosis. There was also an association between the nature of the diagnosis, with an unequivocal diagnosis of autism or Asperger's far more satisfactory than a vague descriptor of 'autistic traits'. Brogan and Knussen (2003) investigated the determinants of satisfaction of 126 parents of the disclosure of a diagnosis of an ASD. They reported that parents were more satisfied with the disclosure if they rated the manner of the professional and quality of information provided positively. In particular, parents were more satisfied when they had been given written information, an opportunity to ask questions and felt that their own concerns had been accepted by the professionals. The findings concurred with Howlin and Moore's (1997) previous study that parents were more satisfied when given a definite diagnosis. Brogan and Knussen (2003) also found that parents were more likely to be satisfied when given the diagnosis of Asperger's, rather than autism. Goin-Kochel, Mackintosh & Myers (2006) reported in their web-based study of nearly 500 parents in the US that parents were more satisfied with the diagnostic process when they saw fewer professionals and when their children received a diagnosis at a younger age. Higher levels of parental education and income were also associated with greater satisfaction.

In a more recent study in Ireland, Braiden, Bothwell & Duffy (2010) reported on several factors that parents reported as contributing to positive experience during the assessment process. These included;

- having their initial concerns listened to
- receiving the child's diagnosis in person
- receiving written information
- help in applying for this information.

Chamak et al. (2011) surveyed nearly 300 French parents to investigate their experience of the autism diagnostic process. In line with previous studies (DeGiacomo and Fombonne, 1998; Goin-Kochel et al., 2006; Howlin and Asgharian, 1999; Siklos and Kerns, 2007), they reported a delay between parents' initial worries, first consultation and diagnosis. Chamak et al. (2011) also reported on the mixed emotions encountered by parents including relief, sadness, anger, distress and dismay. In accordance with the literature in relation to children with developmental disabilities and life threatening illness (Wooley et al., 1989; Sloper & Turner, 1993), the researchers discussed the significance of the manner of the teller, and parents' perception that this had affected their ability to cope with their child's autism. In particular, they noted the importance of providing the diagnosis directly, with a large amount of information and support and concluded that when information was repeated, clarified, and explained in straightforward language, and when a list of support services were given parents felt more satisfied with the consultation. Other studies have reported that parents often comment on the lack of information available about service provisions, such as appropriate education options, social services, leisure activities, health services, financial entitlements and on how these services are accessed and organized (Osborne & Reed, 2008; Renty & Roeyers 2006).

Best practice guidelines on the education and training requirements on appropriate procedures to inform parents of their child's disability include those from the Informing Families Project (2007) in Ireland. The guiding principles are pertinent to discussing a diagnosis of ASD and include:

- Family centred disclosure
- Respect for child and family
- Sensitive and empathetic communication
- Appropriate, accurate information, positive, realistic messages of hope
- Team approach and planning
- Focused and supported implementation of best practice. (National Federation of Voluntary Bodies, 2007).

Clearly it is important to remember that *how* the assessment process is conducted is just as important as *what* is provided.

Parents are often anxious when participating in a consultation where their child’s development is being discussed and assessed. Whilst the assessment process is very familiar to the professionals involved, it is a totally unfamiliar experience for most parents. Parental concern and worry may manifest in a range of ways including sadness, anger or denial. Some parents also report feeling a sense of relief when the diagnosis is finally made after months or years of worry and growing impatience as they wait for the assessment. In line with the principles of family centred practice, it is important to remember that assessment should be collaborative. Professionals should actively involve parents in the assessment by asking them what brings them to the appointment, what their child’s strengths and interests are, and about the concerns they have about their child’s behaviour and development. This knowledge should be used by the professionals during the assessment session and in the report. Terminology should be explained and parents should be actively encouraged to ask questions. It is also helpful if parents are provided with written ’plain speak’ information prior to the assessment. For example:

- Remember that you have valuable information to offer professionals about your child’s play, behaviour, development, daily routine and interests. You may like to bring a list of issues you want to raise and the questions you want to ask
- Where appropriate, it is helpful to have both parents present at the assessment to talk with the professionals and to contribute the different perspectives you may have. It may also be helpful to ask another family member or professional (e.g. early intervention key worker) to the assessment
- At the assessment you will be asked questions about your child’s developmental milestones. To refresh your memory it may be useful to read over your child's Maternal and Child Health Record (the blue book) or perhaps a diary where you may have noted your child's progress
- Bring any professional reports or information with you. This may include information from your child’s care centre, kindergarten, maternal and child health nurse, speech pathologist or GP
- The assessment session will take approximately two hours. Please bring along a drink, snack and any activities that will help your child feel happy and comfortable. We will all stay together in the one room.
- The assessment should be helpful in understanding your child’s development and behaviour, but should also give you information about what to do next – so please ask questions
- You will receive a written report within two weeks of the assessment. If there is anything in the written report that you don’t understand, please call us to discuss further.

## Components of diagnostic assessment for young children usually include:

**Comprehensive medical assessment, for example:**

Audiology, vision, test for genetic disorders

**Developmental and family history, for example:**

Autism Diagnostic Interview – Revised (ADI-R), a semi-structured interview with the child's primary caregiver (Le Couteur et al., 2003).

**Observation of the child's behaviour and interactions, for example:**

Autism Diagnostic Observation Schedule (ADOS-2) a semi-structure play based session with the child (Lord et al., 2000)

**Developmental/cognitive assessment using a standardized test, for example:**

Psycho-Educational Profile – Third Edition (PEP-3), a play based developmental assessment which provides developmental age equivalents for children functioning between 6 months and 7 years, (Schopler et al., 2004).

Wechsler Pre-School and Primary Scale of Intelligence – Third Edition (WPPSI-III), designed for children ages 2 years 6 months to 7 years 3 months (Wechsler, 2002).

**Adaptive functioning, for example:**

Vineland Adaptive Behavioural Scales (VABS-II) **(**Sparrow, Cicchetti, & Balla, 2005)

**Structured language assessment (expressive, receptive, pragmatic), for example:**

Clinical Evaluation of Language Fundamentals - Fourth Edition (CELF-4 Australian), (Wiig, 2006)

Preschool Language Scale, Fourth Edition (PLS-4), (Zimmerman, Steiner & Pond, 2002)

**Assessment of emotions and behaviour, for example:**

Developmental Behaviour Checklist (Einfeld & Tonge, 2002)

**Other assessments to investigate sensory problems, motor planning and co-ordination**

**Comprehensive and sensitive feedback to parents/caregivers**

## ASDs assessment services

### i) Private ASDs assessment

Allied health clinicians (speech pathologist, psychologist, occupational therapists, special education teachers) working in private practice may have the relevant training, experience and expertise to conduct assessments that contribute to the formulation of a diagnosis. The diagnosis of an ASD is formulated by a medical practitioner such as a paediatrician or child psychiatrist. A multi-disciplinary approach to assessment and diagnosis of ASDs is critical. Professional ASD assessment standards are detailed in Autism Victoria Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of ASDs (Autism Victoria, 2009).

- Amaze (Autism Victoria)has a directory of services available through the information line which details private and public sector medical and allied health practitioners with experience in ASDs assessment and diagnosis

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

### ii) Child and Adolescent/Youth Mental Health Services (CAMHS/CYMHS)

Within each region in Victoria there is a specialized child and adolescent ASDs assessment service with a highly skilled multidisciplinary team that provides assessment, diagnosis and treatment planning of ASDs. Each team has a senior clinician to coordinate the ASDs assessment and diagnostic process, oversee the delivery of quality early intervention and ongoing clinical care within the mental health service, and facilitate referral pathways to other appropriate support services. In addition to coordinating service and demonstrating leadership within the mental health service system regarding ASDs, the regional coordinators link in with key service providers such as paediatricians, disability services, early childhood services and student support services officers to assist with local coordination of ASDs service delivery.

## Regional CAMHS/CYMHS ASD Coordinators

| | | | |
|---|---|---|---|
| North east | Kirsty Jungwirth | 9496 3620 | Kirsty.JUNGWIRTH@austin.org.au |
| | | | |
| Inner south | Mary Fleming | 8552 0555 | M.Fleming@alfred.org.au |
| | | | |
| South east Endeavour | David Moseley | 9594 1300 | david.moseley@southernhealth.org.au |
| | | | |
| Eastern | Sian Hughes | 9843 1200 | Sian.Hughes@easternhealth.org.au |
| | | | |
| North west | Frances Saunders<br>Fiona Zandt | 9345 6011 | Frances.Saunders@rch.org.au<br>Fiona Zandt@rch.org.au |
| | | | |
| Orygen | Beth Angus | 1800 888 320 | Beth.Angus@mh.org.au |
| | | | |
| Gippsland | Ruth Turnbull | 5128 0100 | rturnbull@lrh.com.au |
| | | | |
| Barwon | Fiona Walker | 5226 7075 | fionaw@barwonhealth.org.au |
| | | | |
| Glenelg (south west) | Mary-Anne Holley<br>Robert McGregor | 5561 9100 | mholley@swh.net.au<br>RMcGregor@swh.net.au |
| | | | |
| Grampians | Tina Cocking | 5320 3030 | Tinac@bhs.org.au |
| | | | |
| Campaspe & Southern Mallee | Julie Gillin | 5440 6500 | JGillin@bendigohealth.org.au |
| | | | |
| North-east Hume | Susan McLees<br>Jo Freudenstein<br>Megan Hollingworth | 02 6024 7711 | Susan.McLees@wrhs.org.au<br>joanna.freudenstein@awh.org.au<br>megan.hollingworth@awh.org.au |
| | | | |
| Goulburn & Southern | Susan Galambos | 5832 2160 | susan.galambos@gvhealth.org.au |
| | | | |
| Northern Mallee | Mirabel McConchie | 5022 3500 | mcconchiem@ramsayhealth.com.au |

- Child and Adolescent/Youth Mental Health Services (CAMHS/CYMHS)

http://www.health.vic.gov.au/mentalhealth/camhs/

As a tertiary level service, the CAMHS/CYMHS typically see children with more complex, high risk or crisis level needs. CAMHS/CYMHS are not able to meet the demand of ASD assessments alone and work carefully with partners in the private and public sector to meet the shared obligation of assessment and treatment for children and families. CAMHS/CYMHS ASDs coordinators support community partners in their work where possible, and confer on or assess the most complex cases. They serve as an important hub of expertise in ASD assessment and treatment and further support clinicians in their region with professional development and secondary consultation.

The regional CAMHS/CYMHS ASD coordinators are supported by a dedicated state-wide ASDs coordinator located at Mindful: Centre for Training and Research in Developmental Health, University of Melbourne. A training program in assessment, diagnosis and treatment for Paediatric fellows, Psychiatric registrars and mental health clinicians has also been funded by the Department of Health and designed and delivered by Mindful. Regular training is provided on the fundamental of ASDs assessment and diagnosis and is enhanced by follow-up seminars on assessment and treatment for adolescents and young adults, and workshops on specific assessment instruments (e.g. ADOS, PEP-3).

- Mindful: Centre for Training and Research in Developmental Health

http://www.mindful.org.au/

**Other assessment information**

- Raising Children Network' website

The 'Raising Children Network' website has an interactive Autism Service Pathfinder to assist parents and professionals in finding and accessing available services and resources throughout Australia. The pathfinder begins with parent and professional first concerns about a child's behaviour and development and provides flowchart for assessment services and support

http://raisingchildren.net.au/services_pathfinder/services_pathfinder.html

Whilst early and accurate diagnostic evaluation is crucial, ongoing multi-disciplinary assessment should form the basis for individual program planning. This allows parents and professionals to work together to better understand the child's ASD symptoms, developmental profile, emotional and behavioural problems, adaptive skills and strengths and weaknesses across developmental domains. This multi-disciplinary approach to ongoing assessment and planning ensures that both parents and professionals involved share current understanding and knowledge of the child's developmental strengths and weaknesses and can therefore provide relevant intervention. Due to the pervasive nature of ASDs it is vital that there is coordinated input from a multi-disciplinary team in order to include specialized expertise to address the individual's varied needs. As a child progresses through the developmental stages of early childhood, primary school years, adolescence and then adulthood there will be different issues, supports and services for the individual with an ASD and their family. Throughout these stages, ongoing assessment and planning, and a strong commitment from a care team that recognizes that different interventions will be required at various times is required.

## Intervention & education (Early childhood)

As the aetiology of ASDs has not yet been determined in the majority of cases, there is no specific treatment for these complex neuro-developmental conditions. Conflicting opinions over treatment methods continue while researchers attempt to identify what kinds of interventions are most effective, the degree of improvements that can be expected, and if an intervention focussing on one aspect of ASDs results in concurrent improvements in other areas. Francis (2005) stated that, as there is "…no cure at present, the word "treatment" should only be used in a very limited sense, reflecting interventions aimed at helping people with ASD to adjust more effectively to their environment" (p. 493). Consideration must be given to the target of the treatment. That is, does the treatment aim to teach a new skill, increase an existing behaviour, or decrease a behavioural problem? Does the treatment aim to target one of the core features of autism, or perhaps a comorbid condition such as epilepsy or anxiety?

Volkmar et al. (2004) commented that "a major concern is the large, and possibly growing, gap between what science can show is effective, on the one hand, and what treatments parents actually pursue" (p. 155). A clinical report of the American Academy of Pediatrics (Myers & Johnson, 2007) discussed the common use of complementary and alternative medicines for the treatment of young children with ASDs which lack empirically validated research. The report stated that:

> "…families are often exposed to unsubstantiated, pseudoscientific theories and related clinical practices that are, at best, ineffective and, at worst, compete with validated treatments or lead to physical, emotional or financial harm. Time, effort, and financial resources expended on ineffective therapies can create an additional burden on families" (p. 1174).

### Helpful questions for parents

Will the treatment result in harm to my child? (physical or psychological harm)
Is the treatment developmentally appropriate for my child?
How will failure of the treatment affect my child and family?
Has the treatment been validated scientifically?
How will the treatment be integrated in to my child's current program? Freeman (1997)

## Best practice guidelines

A number of best practice guidelines and papers on evidence based treatments and interventions have been published in recent years (Francis, 2005; Howlin, 1998; Jordan et al, 1998; Kanthor et al; National Autism Centre, 2009; National Autistic Society, 2003; Perry & Condillac, 2003; Osborne & Scott, 2004; Roberts & Prior, 2006). These papers provide important information for parents and professionals to assist them in making informed decisions about intervention options.

Some of the core elements of effective educational programs identified in reports on interventions for young children (0-6 years) with an ASD and their families include:

- Family involvement, support and education
- Natural learning environments
- Individualised supports and services
- Systematic instruction
- Predictability and routine
- Structured learning environment
- Specific curriculum focussing on the core symptoms of autism
- Strategies for generalization of skills
- Support at times of transition
- Functional approach to behaviour management
- Emphasis on independent functioning
- The use of visual supports
- Multi-disciplinary collaboration
- Early intervention
- Program intensity

(Dawson & Osterling, 1997; Kanthor et al., 1999; Roberts & Prior, 2006; National Autistic Society, 2003; Rogers & Vismara, 2008)

### i) A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders

An Australian report 'A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders' (Prior, Roberts, Rodger, Williams & Sutherland, 2011) provides a review of the research literature relating to the management and treatment of young children with ASDs to identify the most effective models of best practice. In particular, the report outlines the treatments which are eligible to be funded through the federal government's Helping Children with Autism (HCWA) funding. The funded interventions have good scientific and clinical merits which are likely to contribute to improved outcomes for children (0-7 years) with an ASD and their families.

http://www.fahcsia.gov.au/

### ii) The 'Raising Children Network'

The parent guide to therapies offers reliable information about a wide range of therapies and interventions for children with ASD. Each guide gives an overview of the therapy, what research says about the therapy and the approximate time and costs involved

http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html

### iii) The National Standards Report

In the USA, the National Autism Centre (2009) provided information about the level of scientific evidence that existed in support of educational and behavioural treatments for individuals (0-22 years) with an ASD in the National Standards Report. The report used four levels of strength of evidence (established, emerging, unestablished and ineffective) and was the first to have also provided information about treatment effectiveness based on age, diagnostic group and treatment targets. The National Autism Centre's Standards Report (2009) recommended that parent-professional teams give serious consideration to 'established' treatments, do not begin with 'emerging' treatments, and only consider 'unestablished' treatments after additional research has been conducted and shown favourable outcomes.

Eleven 'established' treatments were identified, of which ten were recognised for children between the ages of 0-6 years. These included:

- an antecedent package
- behavioural package
- comprehensive behavioural treatment
- joint attention intervention, modelling
- naturalistic teaching strategies
- peer training package
- pivotal response treatment
- schedules
- self-management

Thirteen 'emerging treatments were identified for young children between the ages of 0-6 years which included:

- augmentative and alternative communication
- developmental relationship-based treatment
- exercise
- exposure
- imitation based interventions
- language training
- massage/touch therapy
- multi component
- picture exchange communication system
- sign instruction
- social communication
- social skills package
- structured teaching

It is of equal importance for us to be informed about those treatments that are identified as 'unestablished'. Unestablished treatments are described as those for which there is little or no evidence in the scientific literature to draw firm conclusions about the effectiveness of these interventions with individuals with ASD. The NAC guidelines state that "There is no reason to assume these treatments are effective. Further, there is no way to rule out the possibility these treatments are ineffective or harmful" (p. 70). This is because the quality, quantity, and consistency of research findings have generally been poor or do not apply to individuals with ASD.

The following treatments have been identified as having an unestablished level of evidence:

- academic interventions
- auditory integration training
- facilitated communication
- gluten- and casein-free diet
- sensory integrative package

Furthermore, the NAC guidelines state that:

> "There are likely many more treatments that fall into this category. That is, there are many treatments for which no research has been conducted or, if studies have been published, the accepted process for publishing scientific work was not followed. There are a growing number of treatments that have not yet been investigated scientifically. These would all be Unestablished Treatments. Further, any treatments for which studies were published exclusively in non-peer-reviewed journals would be Unestablished "(p.70).

The National Standards Report concluded by concurring with the National Autism Centre's (2001) earlier recommendations which stated:

> "Educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate educational activity toward identified objectives. What constitutes these hours, however, will vary according to a child's chronological age, developmental level, specific strengths and weaknesses, and family needs. Each child must receive sufficient individualized attention on a daily basis so that adequate implementation of objectives can be carried out effectively. The priorities of focus include functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to behaviour problems. To the extent that it leads to the acquisition of children's educational goals, young children with an autistic spectrum disorder should receive specialized instruction in a setting in which ongoing interactions occur with typically developing children" (p. 6).

http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf

## Educational Supports & Services

There are a wide range of education supports and services for *all* young children provided through government, community based services and private practice.  These universal services include kindergartens, playgroups, long day care and local toy libraries.

‘Specialist’ educational services for those young children with an ASD who require additional support, and ‘Intensive’ services for those with complex, high risk or crisis level needs are detailed below.  Most of these services have eligibility criteria based on age, diagnosis or geographical location.

- Early Childhood Intervention Services

Early Childhood Intervention Services (ECIS) support children with a disability or developmental delay from birth to school entry and their families. ECIS provides special education, therapy, counselling, service planning and coordination, and assistance and support to access services such as kindergarten and child care. These services are funded through the Department of Education and Early Childhood Development (DEECD) and provided by Specialist Children's Services (SCS) teams and Early Childhood Intervention agencies (e.g. SCOPE, Yooralla, Noah’s Ark…).

http://www.education.vic.gov.au/ecsmanagement/intervention/default.htm

- Helping Children with Autism

In 2006, the Australian Government committed funding to support families, and their children with an ASD through the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), the Department of Health and Ageing (DOHA), and the Department of Education, Employment and Workplace Relations (DEEWR). Amaze (Autism Victoria)has been appointed to administer this funding in Victoria through the Autism Advisor Program.  A team of Autism Advisors provide help with the funding program and a bi-monthly newsletter which provides updates on the program.

http://www.amaze.org.au/discover/how-we-can-help-you/hcwa/

- Community Health Services

Community Health Services (CHS) provide a range of programs that aim to promote health, wellbeing and independence of children and families. CHS provide a range of paediatric services that include medical (paediatrician), allied health (speech pathology, occupational therapy, dietician…) and family services (counselling, family support, psychology…)

http://www.health.vic.gov.au/pch/

- Kindergarten Inclusion Support Program

Kindergarten Inclusion Support Packages (KISS) are available through the Department of Education and Early Childhood Development (DEECD). The KISS program offers supplementary assistance to support children with severe disabilities or complex medical needs to access and participate in an inclusive kindergarten program.

http://www.education.vic.gov.au/ecsmanagement/careankinder/inclusion/disabilities.htm

- Inclusion and Professional Support Program (IPSP)

The Inclusion and Professional Support Program is available through the Department of Education, Employment and Workplace Relations (DEEWR). The IPSP provides funding to support eligible early childhood education and care services to provide high quality, inclusive environments.

http://www.deewr.gov.au/Earlychildhood/Programs/ChildCareforServices/SupportFamilyCCS/Pages/InclusionSupportProgram.aspx

- Playconnect Playgroups

These autism specific playgroups for preschool children offer play-based learning opportunities for children with ASD as well as the opportunity for their carers to share their experiences.

www.playconnect.com.au

- Kindergarten Inclusion Tip Sheets (Association for Children with a Disability)

Kindergarten Inclusion Tip Sheets are published by thr Association for Children with a Disability (ACD) to promote a positive approach towards including children with disabilities in kindergarten programs. Tip Sheets include parent stories and sheets on a range of topics and are available in several community languages.

http://www.acd.org.au/information/kindergartenb.htm

- Koorie Engagement Support Officers (KESO's)

Koorie Engagement support Officers (KESO's) are employed by DEECD) to support Aboriginal families in accessing services and supports from birth to the time they complete school. KESO's provide advice and support to MCHN, kindergarten programs and schools. KESO's are supported by regional Koorie Education coordinators and a professional development program.

http://www.education.vic.gov.au/about/directions/wannik/programsandreforms/keworkforce.htm

- A Positive Start to School

To support a positive start to school for all children, a common Victorian approach has been developed to guide families, early childhood services and schools. The 'Positive Start to School' initiative aims to develop a shared understanding between families, early childhood services and schools about what is important for children and their families. It includes the completion of a 'Transition Learning and Development Statement' to enable the transfer of information from early childhood and care to primary school.

http://www.education.vic.gov.au/earlylearning/transitionschool/about.htm

- ‘ASD: Planning a successful transition to primary school’ (Brereton & Bull, 2012)

The ‘Autism Spectrum Disorders: Planning a successful transition to primary school’ program has been developed to complement the ‘Positive Start to School’ initiative. This program provides local workshops for parents and educators to attend together to develop a relationship and shared understanding prior to the child’s school commencement. Together, they complete an ‘ASD transition learning and development statement’ as part of a planned approach to transition. Factsheets and ‘ASDs transition learning and development statements’ are also available on the DEECD autism friendly learning website.

http://www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx

- ‘ASD: Planning a successful transition to early childhood education and care’ (Brereton & Bull, 2013)

The Victorian government’s DEECD early childhood intervention branch has funded the development of accompanying teaching materials for one of the other critical transition points; the transition from home to early childhood education and care settings (kindergarten, long day care) .

http://www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx

## Family information, support & education

A common recommendation from all of the ASDs best practice guidelines is that family involvement, support and education is critical (Dawson & Osterling, 1997; Francis, 2005; Howlin, 1998; Jordan et al., 1998; Kanthor et al., 1999; Le Couteur, 2003; National Research Council, 2001; National Autism Centre, 2009; Osbourn & Scott, 2004; Perry & Condillac, 2003; Roberts & Prior, 2006; Rogers & Vismara, 2008; Simpson, 2005). In addition, a key component of family centred practice includes sharing information so that parents can make informed decisions (Dempsey & Keen, 2008; Dunst, 2002; Espe-Sherwindt, 2008; Gabovitch & Curtin, 2009; Shelton & Stepanek, 1994). ASDs specific parent education and training programs can contribute to the management of behavioural problems (Sofronoff & Farbotko, 2002; Whittingham, Sofronoff, Sheffield & Sanders, 2009) and improvement in functional communication in children with an ASD (Koegel, Symon & Koegel, 2002; McConachie, Randle, Hammal & LeCouteur, 2005; Moes and Frea, 2002). Studies have also reported positive effects of education programs in parents of children with an ASD on parental mental health and adjustment and self-efficacy (Bristol & Schopler, 1983; Bristol, 1984; Sofronoff & Farbotko, 2002; Tonge et al., 2006).

Parents can access information, support and education programs through the following:

- Amaze (Autism Victoria) ph. 1300308699

Information pack

A package that provides basic information about ASDs including parents’ perspectives, frequently asked questions, funding options and resources

http://www.amaze.org.au/uploads/2011/08/Information-Pack-Aug-11.pdf

Directory of autism services

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

Family counsellors

Amaze (Autism Victoria)provides telephone or face to face family counselling.
Email: counsellor@amaze.org.au

- ACT-NOW factsheets

The Victorian Government, in conjunction with Monash University, developed an Autism Consultation and Training Strategy (ACT-NOW). Factsheets written for parents and professionals on issues related to children with an ASD and their families are available on the DEECD website.

http://www.education.vic.gov.au/about/directions/autism/default.htm

- Early Days workshops ph. 1300 307 909

For parents and carers of young children who have recently had a child diagnosed with an ASD. Workshops are provided throughout the state, online and by phone.
www.amaze.org.au

- Preschoolers with Autism: An Education & Skills Training Program for Parents (Brereton & Tonge, 2005)

'Preschoolers with Autism' is a 20-week program for parents of young children who have recently been diagnosed with an ASD. Many Victorian ECI services facilitate this programme which is one of the eligible programmes for HCWA funding.

- The 'Raising Children Network'

A website designed to assist parents and professionals in finding and accessing available services and resources throughout Australia. The pathfinder begins with parent and professional first concerns about a child's behaviour and development.

http://raisingchildren.net.au/children_with_autism/children_with_autism_landing.html/highlight/autism

- 'Through the Maze' directory of disability services (ACD)

'Through the Maze' is produced by the Association for Children with a Disability. The directory outlines services and resources in Victoria for parents and children 0-18 years (translations available in community languages). Regional quick guides are also available.

http://www.acd.org.au/information/keycontactb.htm

- Parent Support Workers ph. 1800654013

Available through the Association for Children with a Disability (ACD), parent support workers provide support by listening, understanding (they are themselves parents of children with a disability) and providing information and advice.

http://www.acd.org.au/support/indexb.htm

- Support groups

ASDs specific Parent-to-parent support groups are held throughout metropolitan Melbourne and in rural centres. Groups specifically for fathers, siblings, grandparents and cultural groups are also available. Amaze (Autism Victoria)has a comprehensive list of these groups available on their website.

http://www.amaze.org.au/uploads/2011/08/Victorian-Parent-Support-Groups-Sep-20111.pdf

- Translating and Interpreting Services ph. 131450

The Commonwealth Department of Immigration and Citizenship (DIAC) provide a Translating and Interpreting Services (TIS). TIS National provides a 24-hour, 7-days a week service for individuals and organisation (costs associated). It provides immediate telephone interpreting services, as well as pre-booked telephone and on-site interpreting.

http://www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/

- Nurturing children with autism (Amaze & Playgroups Australia)

‘Nurturing Children with Autism’ is designed to educate and equip the families of young children who have been diagnosed with and ASD with useful information and ideas for play. It contains animations, video clips, information about ASDs and services available.

http://www.amaze.org.au/2012/03/new-nurturing-children-with-autism-resource/

- The Australian Advisory Board on Autism Spectrum Disorders

The Australian Advisory Board on ASDs is the national peak body representing people who have an autism spectrum disorder, their families, carers and helpers. The focus of the Advisory Board is working with governments to develop appropriate policies for people who have an ASD, their families and carers, disseminating information about ASDs and working with the Australian ASD community to build skills.

http://www.autismadvisoryboard.org.au/

- Helping You and Your Family (Association for Children with a Disability)

'Helping You and Your Family' provides information, support and advocacy for parents and children of children with a disability in Victoria. The booklet is available in several community languages and is free for families.

http://www.acd.org.au/information/helpb.htm

- MyTime groups

MyTime groups provide facilitated peer support for parents, grandparents and anyone else caring for children with a disability, developmental delay or chronic medical condition. The groups offer an opportunity to socialise and share ideas and information with others who understand the rewards and intensity of caring for a child with special needs.

http://www.mytime.net.au/

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Clients may come from any non-English background and may come from any age, gender, or religion.

http://www.adec.org.au/advocacy.html

## Respite

At times parents may require respite and a break from the challenging demands of caring for their child with an ASD. This is important as parents may need time out to look after their own needs and to care for their own physical and mental health to enable them to provide optimum care for their child. Extended family members such as grandparents are sometimes able to assist with caring for a child for a few hours, overnight or a weekend. However, not all families have extended family support. There are a wide range of programmes that provide respite services for families of children with a developmental disability.

Respite support is when parents/carers can take a short-term or time-limited break while someone else supports the person with a disability. Respite services aim to provide a positive experience for both the person with a disability and the parent/carer. Respite support can include community participation, in-home support or out of home support.

- Respite Victoria

Respite Victoria has been established as part of the Victorian Department of Human Service's initiatives to improve access to information about respite for carers and people with a disability in Victoria. Respite Victoria has links to the 8 regional disability respite websites in Victoria. Each regional website links you to the Respite Service Search (local and state-wide), and has specific local information, news and events.

http://www.respitevictoria.org.au/what-respite

## Sibling support

The sibling relationship lasts longer than all other human relationships and is the focus of research interest in the general population, as well as when a sibling has a developmental disability such as an ASD. The research findings on the impact of having a sibling with an ASD vary considerably. This may be due to the lack of consistency in research measures, with some studies using parent report, others using self-report, and most using a single type of respondent (Macks & Reeve, 2007).

Some studies have found that the presence of a sibling with an ASD may not be considered a risk-factor for adjustment problems among typically developing siblings (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2011). Other studies have suggested that siblings of individuals with an ASD may even have enhanced psychosocial and emotional development (Kaminsky & Dewey, 2001; Macks & Reeve, 2007). However, other studies report that siblings experience higher levels of internalising behavioural problems and lower levels of prosocial behaviour when compared to siblings of typically developing children or those with other developmental problems (Hastings, 2003; Ross & Cuskelly, 2006). There is an increasingly unfavourable impact on the non-disabled sibling as demographic risk factors, such as socio-economic status or number of siblings increased (Macks & Reeve, 2007). They also suggested that parents have markedly different views from the non-disabled sibling regarding the ways in which siblings' psychosocial and emotional adjustment are affected by the children with autism (Macks & Reeve, 2007). Petalas, Hastings, Nash, Lloyd and Dowey (2009) concurred with earlier studies in their findings that siblings of children with autism had an increased risk of emotional problems, and they also found that these problems persisted over time.

While the findings on the impact of having a sibling with an ASD are inconsistent, what is clear is that siblings are known to have a substantially elevated risk of also having a diagnosis, with evidence of cases of autistic disorder among siblings ranging from 2-6% (Newschaffer et al., 2002). Recent data from prospective studies of developmental trajectories of very young siblings of children with autism indicate strong evidence of early difficulties in cognitive and language development and in social engagement (Elsabbagh & Johnson, 2007; Gamliel, Yirmiya, Jaffe, Manor & Sigman, 2009; Orsmond & Seltzer, 2007; Yirmiya & Ozonoff, 2007).

Sibling relationships change over time in the general population as each sibling moves through different life stages. The symptoms of ASDs also change over time, which may have further implications on the sibling relationship. Clearly, the needs of siblings must be considered in intervention programmes. Siblings need developmentally appropriate information and support. There are siblings support groups and information available through local and state-wide services, including online social-networking sites.

- Association for Children with a Disability

Provides a range of factsheets, booklets and access to local sibling support programmes.

http://www.acd.org.au/siblings/indexb.htm

- Sisters Individuals Brothers (SIBS)

Information and resources for primary school aged and adolescents with a brother or sister with a disability or chronic illness available through Association for Children with a Disabilit.y

www.sibs.org.au

- The Royal Australian and New Zealand College of Psychiatrists

The Royal Australian and New Zealand College of Psychiatrists (RANZCP), through the work of its Faculty of Child and Adolescent Psychiatry (FCAP), has recently published a position statement: Addressing the needs of siblings of children with disability or chronic illness.

http://www.ranzcp.org/policy-advocacy/addressing-the-needs-of-siblings-of-children-with-disability-or-chronic-illness.html

## Financial Support

Families of children with an ASD are reported to have greater financial burden compared with other children with special health care needs (Jabrink, Fombonne & Knapp, 2003; Kogan et al., 2008). In particular, Kogan et al. (2008) found that parents report the need for additional income for their child's care and are more likely than parents of children with other health care needs to reduce or stop work due to their child's disability. Parent/carers of a young child with an ASD in Victoria can access financial support through the following:

- The Carer Allowance (Centrelink)

The Carer Allowance (not means tested) assists parents of a child with a disability financially and can be applied for through Centrelink. Children with the diagnoses of Asperger syndrome and Autism are recognised disabilities indicating eligibility and no requirement for further medical assessment until the child's 16th birthday. Those children who have not yet received a diagnosis may also be eligible and can apply for the allowance.

http://ww.centrelink.gov.au/internet/internet.nsf/forms/ci002.htm

- Chronic Disease Management Plan (CDMP) (Medicare)

The Chronic Disease Management Plan provides five sessions with an allied health professional per calendar year including funding for dental treatment. The CDM plan can be written by a GP.

http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement

- Mental Health Care Plan (Medicare)

Medicare rebate through a Mental Health Care Plan provides six sessions with an allied health professional. An additional four session may also be available in exceptional circumstances. Ten group sessions with an allied health professional are also available. This is available for the individual with an ASD, parents, siblings and carers.

http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-b-better

- Assessment (Medicare)

Medicare rebate through the commonwealth 'Helping Children with Autism' funding is available for four appointments for assessment with a private practitioner/s. Practitioners may include a paediatrician, psychiatrist, psychologist, speech pathologist, occupational therapist, audiologist, optometrist, audiologist, orthoptist or physiotherapist.

- Helping Children with Autism Treatment (Medicare)

Medicare rebate is available for 20 sessions with an allied health practitioner following a diagnosis of a PDD. The plan must be written by the child's 13th birthday and used by their 15th birthday.

http://www.fahcsia.gov.au/sa/disability/progserv/people/HelpingChildrenWithAutism/Pages/default.aspx

- Flexible Support Packages (FSP)

Flexible support packages are provided through DEECD to assist young children with complex support needs who require additional services and supports not usually available through community services. FSPs are specifically designed to provide time-limited, individualised support to address a specific need(s) unable to be fully met by ECIS. Families with children eligible for ECIS may apply for an ECIS Flexible Support Package.

http://www.education.vic.gov.au/ecsmanagement/intervention/services/packages.htm

- Amaze (Autism Victoria) information pack

This information package provides basic information about funding options and financial supports

http://www.amaze.org.au/uploads/2011/08/Information-Pack-Aug-11.pdf

## Professional information, support & education

There is an increasing range of information, education and support for professionals working in Victoria with young children with an ASD and their families.

- Regional Autism Consultation and Training Teams (ReACTs) or Regional Autism Planning Teams (RAPT)

Regional Autism Coordination Teams (ReACTs) or Regional Autism Planning Teams (RAPT) teams identify and respond to the ASDs training and consultation needs in their local areas. DEECD has employed nine ReACT or RAPT Coordinators.

| REGION | COORDINATORS | EMAIL |
|---|---|---|
| North | Priscilla Parodi | parodi.priscilla.p@edumail.vic.gov.au |
| South | Cecilia Morales | morales.cecilia.a@edumail.vic.gov.au |
| East | Anne Kettle | kettle.anne.t@edumail.vic.gov.au |
| West | Anne Butterworth | butterworth.anne.a@edumail.vic.gov.au |
| Hume | Jenny Drysdale | drysdale.jennifer.m@edumail.vic.gov.au |
| Grampians | Desley Beechley | beechey.desley.j@edumail.vic.gov.au |
| Loddon-Mallee | Angela Walsh-Edgar | walsh-edgar.angela.t@edumail.vic.gov.au |
| Gippsland | Naomi Licciardello | Licciardello.naomi.w@edumail.vic.gov.au |
| Barwon South-West | Jann Kirkland | Kirkland.jann.e@edumail.vic.gov.au |

- Communities of Practice (Disability Services)

Case Consultation Practitioners are employed by DHS in each region across Victoria. They are responsible for providing secondary consultation to disability case managers and developing or building on existing local networks to enhance linkages and pathways. They have also created 'communities of practice' to provide a means of continual learning and development for disability services staff. Case consultant practitioners are based at various organisations across Victoria.

| REGION | ORGANISATION | EMAIL |
|---|---|---|
| **North/West** | Autism Vic. | www.amaze.org.au/learning |
| **South** | Windermere | www.windermere.org.au |
| **East** | Autism Vic. | www.amaze.org.au/learning |
| **Hume** | Mansfield Autism Statewide Services | www.autismmansfield.org.au |
| **Loddon-Mallee** | Community Living & Respite Services Inc. | www.clrasd.org.au |
| **Gippsland** | SCOPE | https://sites.google.com/site/autismgippsland/ |
| **Barwon S-W** | Gateways<br>MPOWER | www.gateways.com.au<br>www.mpower.org.au |

http://www.amaze.org.au/uploads/2012/01/ASD-Case-Consultant-Practitioners-01-12.pdf

- The Autism Secondary Consultation and Training Strategy (ACT-NOW)

The Autism Secondary Consultation and Training Strategy (ACT-NOW) was developed by Monash University in 2005 to build professionals skills and knowledge by helping service providers to more effectively identify ASDs, promote an understanding of ASDs within the wider community and provide a range of professional development opportunities. The strategy was funded by DEECD. Whilst Monash University finished the ACT-NOW strategy in 2011, factsheets are still available on the website.

http://www.med.monash.edu.au/spppm/research/devpsych/actnow/

- ‘ASDs in the preschool years’ (Brereton, Bull & Tonge, 2009).

Training materials have been developed through the ACT-NOW strategy for three 2-hour workshops for early childhood educators and parents to support the inclusion of young children with an ASD in early childhood education and care services. ECIS practitioners throughout the state have been trained and accredited to deliver the workshops in local areas. Workshops are advertised through the ReACT/ RAPT Coordinators.

http://www.med.monash.edu.au/spppm/research/devpsych/actnow/asds-preschool.html

- ASDs training program: Mindful, Centre for Training and Research in Developmental Health. The University of Melbourne.

A training program in assessment, diagnosis and treatment for Paediatric fellows, Child and Adolescent Psychiatry registrars and mental health clinicians has been funded by DoH (Victoria) and designed and delivered by Mindful. Regular training is provided on the fundamental of ASDs assessment and diagnosis and is enhanced by follow-up seminars (e.g. ADOS, PEP-3).

http://www.mindful.org.au/Home.aspx

- Amaze (Autism Victoria) workshops, courses and information

Providing training workshops, courses, information sessions and other training opportunities is one of the primary activities of Amaze. Amaze Knowledge delivers a range of structured and personalized education courses for services and organizations directly involved in supporting individuals and families with an ASD. They also have a certified training course and arrange national and international speakers for conferences and special events.

http://www.amaze.org.au/discover/how-we-can-help-you/learning-education/

- Working with individuals with an ASD. Amaze (Autism Victoria)

Amaze (Autism Victoria) has information on their website on issues related to working with individuals with an ASD. There is specific information for the Professional Autism Community, Medical & Allied Health Professionals, Schools, the Emergency Services and for those Working in the Justice System.

http://www.amaze.org.au/discover/working-with-individuals-on-the-spectrum/

## Other considerations (Early childhood)

All children diagnosed with autism have problems in the core areas of communication, social skills and restricted and repetitive patterns of play and behaviour, Some young children with an ASD also have associated features such as sleep problems, fussy eating, sensory disturbance or motor impairment that also occur in children with other developmental problems and are not specific to children with an ASD.

### Associated features of ASDs

#### Sleep problems

Reports of sleep problems in children with an ASD range from 40% - 80% compared to 30% for typically developing children (Goodlin-Jones et al., 2009). Parents of children with an ASD commonly report problems with their child going to bed, falling asleep and waking frequently, which are associated with disruptive daytime behaviour and increased family stress (Richdale, Francis, Gavidia-Payne & Cotton, 2000).

#### Motor impairment

Recent research is investigating whether neuro-developmental problems involving motor dysfunction are an additional core behavioural symptom of ASDs (Ming, Brimacombe & Wagner, 2007). The literature describes delayed motor milestones, clumsiness, poor co-ordination, impaired postural control, awkward gait and motor planning problems in children with an ASD (Ghaziuddin, Butler, Tsai & Ghaziuddin, 1994; Green et al., 2002; Ming, Brimacombe & Wagner, 2007; Mostofsky, Burgess, & Gidley Larson, 2007; Rinehart et al., 2001; Rinehart et al., 2006). Van Waelvelde (2010) has also reported consistency of poor motor performance in children with autism over time.

## Fussy eating

While fussy eating can be a normal part of early childhood development,  children with autism exhibit more eating and meal-time problems and eat fewer foods from each food group (fruits, dairy, vegetables, proteins, starches), than typically developing children (Schreck et al., 2004). Whilst there have been numerous reports on fussy eating in children with an ASD, few have provided systematic objective evaluations of either the prevalence or nature of their feeding problems. However, the range of concerns described by parents and reported in the literature generally relate to food/liquid selectivity based on presentation or type,  food refusal, and concerns about unusual mealtime behaviours, such as sniffing or inspecting foods, gorging, hording or gagging. When eating problems persist and parents are concerned about their child's nutritional intake, a consultation with a medical practitioner (GP) is advised. Dieticians working in Early childhood intervention Services or in Community Health Centre's can also be helpful.

## Sensory disturbance

Sensory problems are often associated with ASDs, but may also occur in children with other developmental problems and are not specific to children with an ASD. Autobiographical accounts from adults with High Functioning Autism have been published and report unusual responses to sensory stimuli (Grandin, 1995). Sensory problems are described as contributing to high levels of distress, fear and anxiety, which disrupt daily life and social functioning, but also as a source of pleasure and safety (O'Neill & Jones, 1997). Research studies on sensory problems for individuals with autism are limited compared to studies of other aspects of development and often suffer from methodological limitations. However, empirical studies suggest that sensory problems are present in most children with autism and they manifest very early in development (Baranek, 2002).

The criteria for the proposed DSM-V includes a new category of hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (APA, 2011).

## Associated conditions

### Developmental delay

Children under the age of six with developmental and learning problems are usually described as having a developmental delay rather than an intellectual disability which is the term used when children are older and can be tested on formal cognitive assessments. The majority of young children with autism (approximately 70%) also have a developmental delay and typically have an uneven profile of abilities.

While young children with ASDs can be difficult to assess using standardised cognitive assessments, there are play-based developmental assessments designed specifically for very young children (e.g. Psycho-Educational Profile) which provide information about a child's current developmental strengths and weaknesses.

### Attention Deficit Hyperactivity Disorder (ADHD)

Attention Deficit Hyperactivity Disorder (ADHD) is a childhood-onset disorder with three main subtypes; hyperactive, inattentive and mixed (DSM-IV-TR, APA, 2000). Whilst causality is unknown, it occurs more frequently in individuals with epilepsy (Hesdorffer et al., 2004) and developmental disabilities (Ghaziuddin, 2005). DSM-IV-TR (APA, 2000) has a caveat that ADHD should not be diagnosed concurrently with autism although this is likely to be changed in DSM-V (APA, 2011).  Studies indicate that co-occurrence of ADHD and autism symptoms is common, (Kim et al, 2000; Goldstein & Schwebach, 2004; Loveland & Tunali-Kotoski, 1997; Rinehart & Tonge, 2007; Rommelse, Franke, Geurts, Hartman & Buitelaar, 2010; Simonoff et. al., 2006) with at least 30% of children with an ASD experiencing significant problems with distractibility, inattention, impulsiveness, fidgetiness and motor over- activity (Goldstein  &  Schwebach, 2004; Reierson et al., 2007). ADHD symptoms, which also interfere with learning and social interactions, generally reduce as the child matures (Tonge & Rinehart, 2006).

## Epilepsy

There is a known association between autism and epilepsy with prevalence rates of epilepsy in those with autism varying from 5% - 40% compared to the general population of .5% - 1% (Amiet et al., 2008). The risk for epilepsy in autism is higher for girls and for individuals who also have an intellectual disability (Amiet, et al, 2008) and also for those who have had a traumatic birth (Larson et al., 2005).. Peak periods of seizure onset are reported to be in early childhood and adolescence (Tuchman & Rapin, 2002).

| | |
|---|---|
| Epilepsy Foundation of Australia | http://www.epinet.org.au/ |

## Fragile X Syndrome and Tuberous Sclerosis

Fragile X and Tuberous Sclerosis are recognised as being associated with autism in a small proportion of individuals (Volkmar & Klin, 2005). Despite previous reports, recent surveys do not suggest any particular association between autism and cerebral palsy, phenylketonuria, congenital rubella or Down syndrome (Fombonne, 2005).

| | |
|---|---|
| Fragile X Association of Australia | http://www.fragilex.org.au/ |
| Australasian Tuberous Sclerosis Society | http://www.atss.org.au/ |

## Mental health and emotional and behavioural wellbeing

Children with an ASD are at risk of significantly higher levels of emotional and behavioural problems compared to their typically developing peers, and also those with an I.D. (Bradley et al., 2004; Brereton, Tonge & Einfeld, 2006; Lainhart & Folstein, 1994; Smalley, McCracken & Tanguay, 1995; Steinhausen & Metzke, 2004). Emotional and behavioural problems (psychopathology) in toddlers, children and adolescents with ASDs has been found to contribute to maternal stress and parental mental health problems (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hastings et al., 2005; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Tonge & Einfeld, 2003). The emotional and behavioural problems most often associated with ASDs in early childhood is anxiety.

Anxiety disorders differ from fears and worries, (which are common in individuals with an ADS), in the level of severity, associated distress and life interference. Studies report high rates of anxiety disorders in individuals with an ASD (Fombonne, 1992; Gillot et al., 2001; Nick et al., 2000; Simonoff et. al., 2008). In addition to generalized anxiety disorder, individuals with an ASD can also develop distinct anxiety disorders such as obsessive compulsive disorder and post traumatic stress disorder (Ghaziuddin, 2005). Symptoms of anxiety, (e.g. fears, resistance to change, panic, phobias, tenseness, shyness, irritability and somatic symptoms) cause distress and impairment for the individual, but also have the potential to disrupt education, further impair social interaction and create management problems and stress for the parents and carers. Individuals with symptoms of anxiety may respond to cognitive and behavioural treatment approaches and also to pharmacological treatments (Tonge & Einfeld, 2003).

➢ The Developmental Behaviour Checklist (DBC) measures emotional and behavioural problems in children with developmental disabilities. There is both a 96 item parent-completed questionnaire (DBC-P) and a teacher version of the DBC (DBC-T) which allows educators to provide valuable additional information about the child in a kindergarten setting. The DBC-P has been translated into other languages: Arabic, Chinese, Croatian, Dutch, Finnish, French, German, Greek, Hindi, Italian, Japanese, Malay, Norwegian, Portuguese, Portuguese (Brazil), Spanish, Swedish, Turkish and Vietnamese. The DBC-T has been translated into Spanish, Dutch, French and Finnish.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

## Cultural awareness

Culture is "the shared way of life including attitudes, beliefs, norms and values of people" (Powie, 2012, p. 63).There are inevitable stressors for people who are adapting to a new country, culture, social system and language. Families from culturally and linguistically diverse (CALD) backgrounds may experience stressors due to settlement issues, trauma, pre-post immigration experiences, unemployment, limited social support and poverty (Baasiri & Carroll, 2011). There may be additional cultural complexities to the adjustment and wellbeing of individuals with a disability, including those with an ASD, and their families. Cultural differences in family members' responses to disability have been reported to influence levels of stress and long-term outcomes (Echemendia & Westerveld, 2006). Culturally awareness and sensitivity is important in the fields of disability and mental health. Baasir & Carroll (2011) stated that "Clinicians need to adjust the way they provide health and mental health services, using knowledge of the culturally mediated values, attitudes, and experiences that apply to a given case, and through effective communication skills, and a willingness to advocate on behalf of families" (p. 44).

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Clients may come from any non-English background and may come from any age, gender, or religion.

http://www.adec.org.au/advocacy.html

- Cultural Diversity Plan for Victoria's Specialist Mental Health Services (DoH)

The Cultural Diversity Plan for Victoria's Specialist Mental Health Services provides a framework for improving the accessibility and responsiveness of mental health services to Victoria's culturally and linguistically diverse communities. The Cultural Diversity Guide identifies a range of strategies to improve cultural responsiveness, recognising that no single strategy suits every program and agency and there are many different pathways to equitable, high quality service provision. It provides examples of good practice, as well as guidance on additional resources and supports to respond to diversity for programs and agencies.

http://www.health.vic.gov.au/diversity/cald.htm

# SECTION FOUR

## Childhood (The primary school years)

## Identification & referral (Childhood)

### Developmental concerns in the primary school years

While there has been a focus on early identification, assessment and diagnosis of ASDs over the past several years, it is still common for children to be diagnosed in the primary school years. This is particularly so for those children with Asperger's disorder who have not had a history of delayed cognitive or language development. For these children, it is often not until they attend kindergarten or school that their social and behavioural difficulties become more apparent. The social demands of a busy classroom and playground become more complex and difficult for the child with Asperger's disorder to navigate. This may also be the case for school-aged children with high functioning autism (HFA). These difficulties often lead to discussion between parents and teachers about their concerns.

For some parents, the degree of difficulty their child is having at primary school is surprising as their child has functioned very well in the informal kindergarten environment and at home where there are not the social demands of a large peer group. Other parents have had nagging worries about their child for many years and welcome the opportunity to discuss the way forward.

## Screening

Screening involves the use of specific tests or examinations to identify those people in a population who are likely to have a particular condition or disorder (Baird et al., 2001; Oberklaid at al., 2002). Screens are not diagnostic, but sort out those who are likely to have the condition from those who are not. Screening instruments can provide valuable information about a child's development and behaviour and can provide a structure for parents and professionals to talk about their understanding of the child in different settings. This is an important 'first step' in informing parents and professionals of the need for referral for further assessment.

- The Developmental Behaviour Checklist (DBC)

The Developmental Behaviour Checklist (DBC-P) is a parent-completed, reliable and valid autism screening tool for at-risk populations (Einfeld & Tonge, 2002). The DBC Autism Screening Algorithm (DBC-ASA) is a twenty-nine item scale used for discriminating children and young people (aged 4-18) with autism (Brereton et al., 2002). The DBC-P (parent) has been translated into other languages, including Arabic, Chinese, Croatian, Dutch, Finnish, French, German, Greek, Hindi, Italian, Japanese, Malay, Norwegian Portuguese, Portuguese (Brazil), Spanish, Swedish, Turkish and Vietnamese.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

## Referral

Referral and support should take place as soon as there is a concern about a child's development or behaviour. It is not necessary to wait for a diagnosis of an ASD to seek help. In Victoria there are a number of referral pathways when parents and professionals are concerned about a child's development and behaviour. This makes it confusing for parents and professionals alike. When concerns are raised, a referral with supporting documentation can be made by parent/s or professionals to one or several of the following services.

### i) General Practitioners

School aged children are often referred to the local GP when there is a concern about behaviour and development. Referral to a GP should include relevant supporting documentation and an indication of specific concerns and desired outcome (e.g. referral to paediatrician). GPs can conduct and initial medical assessment and use a screening instrument to guide further referral where appropriate. Ongoing referral may be to a medical specialist such as a Paediatrician or Child Psychiatrist, to an allied health practitioner, or to an ASDs assessment service such as CAMHS/CYMHS. GPs can also complete the necessary documentation for access to Medicare rebates for allied health services, assessment services and support through Centrelink. GPs have a critical role in the ongoing monitoring of health issues over the lifespan for those children diagnosed with an ASD.

### ii) Student Support Services Officers

The student support services officer (SSSO) program is funded by the DEECD to provide specialised support for children and young people with additional needs or at risk of disengagement and their families in government schools. The program also aims to strengthen the capacity of schools to engage all students in education. SSSOs include psychologists, guidance officers, speech pathologists, social workers, visiting teachers and other related professionals who may conduct initial assessment and provide ongoing support for the student and school staff.

http://www.education.vic.gov.au/healthwellbeing/support/ssso.htm

### iii) Community Health Services

Community Health Services (CHS) provide a range of programs that aim to promote health, wellbeing and independence of children and families. CHS provide a range of paediatric services that include allied health (speech pathology, physiotherapy, occupational therapy, dietician…) and family services (counselling, family support, psychology…)

http://www.health.vic.gov.au/pch/

### iv) Allied Health Practitioners

Referral may also be made to an allied health practitioner such as a Speech Pathologist, Psychologist, Special Education Teacher or Occupational Therapist for assessment and intervention. Therapists and specialist teachers typically work within a local community health centre or through a private practice. Initial assessment from an allied health practitioner may also later be used to contribute to a diagnosis.

- Australian Psychological Society

http://www.psychology.org.au/findapsychologist/

- Occupational Therapy Australia

http://www.otaus.com.au/findanot

- Speech Pathology Australia

http://www.speechpathologyaustralia.org.au/about-spa/find-a-speech-pathologist

## Other referral information

- The ‘Raising Children Network’ website has an interactive Autism Service Pathfinder to assist parents and professionals in finding and accessing available services and resources throughout Australia. The pathfinder begins with parent and professional first concerns about a child’s behaviour and development.

http://raisingchildren.net.au/services_pathfinder/services_pathfinder.html

- Amaze (Autism Victoria) has a directory of services available through the information line.

Ph. 1300308699

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

- The Association for Children with a Disability (ACD) has a comprehensive booklet titled ‘Through the Maze’ which outlines services and resources in Victoria for parent and children 0-18 years (translations available in community languages)

http://www.acd.org.au/information/ttmb.htm

# Assessment & Diagnosis (Childhood)

## ASDs assessment guidelines

Timely and accurate diagnosis can provide an understanding of the child's behaviour and development, guidance for home, school and community interventions, a response to the needs of siblings who are 'at risk' of poor developmental outcome and access to services and support for the child and family.

Diagnosing ASDs is challenging for professionals as there is not a simple diagnostic test that provides a definitive answer. Because the aetiology of ASDs is largely unknown, diagnosis relies on diagnostic criteria being matched with behavioural description, observation of behaviour patterns and the child's course of development. A comprehensive multi-disciplinary assessment should always include expert clinical judgment combined with a range of valid and reliable standardized instruments. Currently, the international classification standard for establishing a diagnosis of autism and other pervasive developmental disorders is outlined in both the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revised, of the American Psychiatric Association (DSM-IV-TR) (APA, 2000) and the International Classification of Diseases and Related Health Problems (ICD-10) (WHO 1992).

Assessment and diagnosis of school aged children presents with particular challenges. Children with an ASD present differently depending on their current symptoms which change over time, their language and cognitive ability. Co-morbid conditions may 'over-shadow' the diagnosis of an ASD, so that parents and professionals may attribute all of the child's presenting behaviour to a pre-existing diagnosis such as ADHD, rather than as an additional condition. Other diagnoses also need to be considered. Common differential diagnosis and/or co-morbid conditions during childhood include hearing impairment, language disorders, attention deficit disorders, behavioural disorders, and attachment disorder. Thorough assessment by professionals with experience and expertise in ASDs is required to understand coexisting and alternative conditions (New Zealand Ministry of Health and Education, 2008).

ASDs are complex disorders and undertaking an ASD assessment requires a rigorous, comprehensive and systematic approach. Professionals involved in ASD assessments require training, experience and supervision.  In Victoria, ASDs assessment guidelines have been developed by Autism Victoria (2009). The 'Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders'  provide a definition of ASDs, outline assessment standards and guidelines, and list eligibility criteria for government funded services. The guidelines advocate a multi-disciplinary approach to assessment using DSM-IV-TR criteria.

- Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders'

http://www.amaze.org.au/uploads/2010/11/ASD-Diagnosis-Assessment-Guidelines-Victoria.pdf

Whilst Autism Victoria's (2009) diagnostic process guidelines provide standards, the process of assessment varies from one service or clinic to another and, as such, children and their families have different experiences. International studies have shown that parents are sometimes dissatisfied with the assessment process, and also with how the diagnosis was communicated to them (Chamak, Bonniau, Oudaya & Ehrenberg, 2011; Goin-Kochel et al., 2006; Howlin & Moore, 1997). The time of diagnosis is a critical time when parents are told their child has a lifelong disability . It is an experience that parents don't forget. It is suggested that the manner in which professionals discuss the diagnosis with parents may affect the parents ability to cope and adapt, as well as their perception and subsequent care of their child (Silove, 2011).

Howlin and Moore (1997) surveyed 1,295 parents of children aged 2-49 years in the UK to investigate their views of the diagnostic process. Results indicated that parents were frustrated by lengthy delays, with parental satisfaction with the diagnostic process reported to be affected by the length of time they waited before receiving a final diagnosis. There was also an association between the nature of the diagnosis, with an unequivocal diagnosis of autism or Asperger's far more satisfactory than a vague descriptor of 'autistic traits'.  Brogan and Knussen (2003) investigated the determinants of satisfaction of 126 parents of the disclosure of a diagnosis of an ASD. They reported that parents were more satisfied with the disclosure if they rated the manner of the professional and quality of information provided positively. In particular, parents were more satisfied when they had been given written information, an opportunity to ask questions and felt that their own concerns had been accepted by the professionals. The findings concurred with Howlin and Moore's (1997) previous study that parents were more satisfied when given a definite diagnosis. Brogan and Knussen (2003) also found that parents were more likely to be satisfied when given the diagnosis of Asperger's, rather than autism. Goin-Kochel, Mackintosh & Myers (2006) reported in their web-based study of nearly 500 parents in the US that parents were more satisfied with the diagnostic process when they saw fewer professionals and when their children received a diagnosis at a younger age. Higher levels of parental education and income were also associated with greater satisfaction.

In a more recent study in Ireland, Braiden, Bothwell & Duffy (2010) reported on several factors that parents reported as contributing to positive experience during the assessment process. These included:

- having their initial concerns listened to
- receiving the child's diagnosis in person
- receiving written information
- help in applying for this information.

Chamak et al. (2011) surveyed nearly 300 French parents to investigate their experience of the autism diagnostic process. In line with previous studies (DeGiacomo and Fombonne, 1998; Goin-Kochel et al., 2006; Howlin and Asgharian, 1999; Siklos and Kerns, 2007), they reported a delay between parents' initial worries, first consultation and diagnosis. Chamak et al. (2011) also reported on the mixed emotions encountered by parents including relief, sadness, anger, distress and dismay. In accordance with the literature in relation to children with developmental disabilities and life threatening illness (Wooley et al., 1989; Sloper & Turner, 1993), the researchers discussed the significance of the manner of the teller, and parents' perception that this had affected their ability to cope with their child's autism. In particular, they noted the importance of providing the diagnosis directly, with a large amount of information and support and concluded that when information was repeated, clarified, and explained in straightforward language, and when a list of support services were given parents felt more satisfied with the consultation. Other studies have reported that parents often comment on the lack of information available about service provisions, such as appropriate education options, social services, leisure activities, health services, financial entitlements and on how these services are accessed and organized (Osborne & Reed, 2008; Renty & Roeyers 2006).

Best practice guidelines on the education and training requirements on appropriate procedures to inform parents of their child's disability include those from the Informing Families Project (2007) in Ireland. The guiding principles are pertinent to discussing a diagnosis of ASD and include:

- Family centred disclosure
- Respect for child and family
- Sensitive and empathetic communication
- Appropriate, accurate information, positive, realistic messages of hope
- Team approach and planning
- Focused and supported implementation of best practice.

(National Federation of Voluntary Bodies, 2007).

Clearly it is important to remember that *how* the assessment process is conducted is just as important as *what* is provided.

Parents are often anxious when participating in a consultation where their child's development is being discussed and assessed. Whilst the assessment process is very familiar to the professionals involved, it is a totally unfamiliar experience for most parents. Parental concern and worry may manifest in a range of ways including sadness, anger or denial. Some parents also report feeling a sense of relief when the diagnosis is finally made after months or years of worry and growing impatience as they wait for the assessment. In line with the principles of family centred practice, it is important to remember that assessment should be collaborative. Professionals should actively involve parents in the assessment by asking them what brings them to the appointment, what their child's strengths and interests are, and about the concerns they have about their child's behaviour and development. This knowledge should be used by the professionals during the assessment session and in the report. Terminology should be explained and parents should be actively encouraged to ask questions.

It is also helpful if parents are provided with written ’plain speak’ information prior to the assessment. For example:

- Remember that you have valuable information to offer professionals about your child’s behaviour, development, daily routine and interests. You may like to bring a list of issues you want to raise and the questions you want to ask
- Where appropriate, it is helpful to have both parents present at the assessment to talk with the professionals and to contribute the different perspectives you may have. It may also be helpful to ask another family member or professional (e.g. school teacher) to the assessment
- At the assessment you will be asked questions about your child’s developmental milestones. To refresh your memory it may be useful to read over your child's Maternal and Child Health Record (the blue book) or perhaps a diary where you may have noted your child's progress
- Bring any professional reports or information with you. This may include information from your child’s school, speech pathologist, paediatrician or GP
- The assessment session will take approximately two hours. Please bring along a drink, snack and any activities that will help your child feel happy and comfortable.
- The assessment should be helpful in understanding your child’s development and behaviour, but should also give you information about what to do next – so please ask questions
- You will receive a written report within two weeks of the assessment. If there is anything in the written report that you don’t understand, please call us to discuss further.

## Components of diagnostic assessment for primary school aged children usually include:

**Comprehensive medical assessment, for example:**
Audiology, vision, test for genetic disorders

**Developmental and family history, for example:**
Autism Diagnostic Interview – Revised (ADI-R), a semi-structured interview with the child's primary caregiver (Le Couteur et al., 2003).

**Observation of the child's behaviour and interactions, for example:**
Autism Diagnostic Observation Schedule (ADOS) a semi-structure play based session with the child (Lord et al., 2000)

**Developmental/cognitive assessment using a standardized test , for example:**
Wechsler Pre-School and Primary Scale of Intelligence – Third Edition (WPPSI-III), designed for children ages 2 years 6 months to 7 years 3 months (Wechsler, 2002).
Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV), for children between the ages of 6 and 16 years (Wechsler, 2003).

**Adaptive functioning, for example:**
Vineland Adaptive Behavioural Scales (VABS-II) **(**Sparrow, Cicchetti, & Balla, 2005)

**Structured language assessment (expressive, receptive pragmatic language , for example:**
Clinical Evaluation of Language Fundamentals - Fourth Edition (CELF-4 Australian), (Wiig, 2006)

**Assessment of emotions and behaviour, mental health examination, for example:**
Developmental Behaviour Checklist (Einfeld & Tonge, 2002)

**Other assessments to investigate sensory problems, motor planning and co-ordination**

**Comprehensive and sensitive feedback to the parents/caregivers, and child where appropriate**

## ASDs assessment services

### i) Private ASDs assessment

Allied health clinicians (speech pathologist, psychologist, occupational therapists, special education teachers) working in private practice may have the relevant training, experience and expertise to conduct assessments that contribute to the formulation of a diagnosis. The diagnosis of an ASD is formulated by a medical practitioner such as a paediatrician or child psychiatrist. A multi-disciplinary approach to assessment and diagnosis of ASDs is critical. Professional ASD assessment standards are detailed in Autism Victoria Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of ASDs (Autism Victoria, 2009).

- Amaze (Autism Victoria) has a directory of services available through the information line which details private and public sector medical and allied health practitioners with experience in ASDs assessment and diagnosis

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

### ii) Child and Adolescent/Youth Mental Health Services (CAMHS/CYMHS)

Within each region in Victoria there is a specialized child and adolescent ASDs assessment service with a highly skilled multidisciplinary team that provides assessment, diagnosis and treatment planning of ASDs. Each team has a senior clinician to coordinate the ASDs assessment and diagnostic process, oversee the delivery of quality early intervention and ongoing clinical care within the mental health service, and facilitate referral pathways to other appropriate support services. In addition to coordinating service and demonstrating leadership within the mental health service system regarding ASDs, the regional coordinators link in with key service providers such as paediatricians, disability services, early childhood services and student support services officers to assist with local coordination of ASDs service delivery.

## Regional CAMHS/CYMHS ASD coordinators

| | | | |
|---|---|---|---|
| North east | Kirsty Jungwirth | 9496 3620 | Kirsty.JUNGWIRTH@austin.org.au |
| | | | |
| Inner south | Mary Fleming | 8552 0555 | M.Fleming@alfred.org.au |
| | | | |
| South east Endeavour | David Moseley | 9594 1300 | david.moseley@southernhealth.org.au |
| | | | |
| Eastern | Sian Hughes | 9843 1200 | Sian.Hughes@easternhealth.org.au |
| | | | |
| North west | Frances Saunders<br>Fiona Zandt | 9345 6011 | Frances.Saunders@rch.org.au<br>Fiona Zandt@rch.org.au |
| | | | |
| Orygen | Beth Angus | 1800 888 320 | Beth.Angus@mh.org.au |
| | | | |
| Gippsland | Ruth Turnbull | 5128 0100 | rturnbull@lrh.com.au |
| | | | |
| Barwon | Fiona Walker | 5226 7075 | fionaw@barwonhealth.org.au |
| | | | |
| Glenelg (south west) | Mary-Anne Holley<br>Robert McGregor | 5561 9100 | mholley@swh.net.au<br>RMcGregor@swh.net.au |
| | | | |
| Grampians | Tina Cocking | 5320 3030 | Tinac@bhs.org.au |
| | | | |
| Campaspe & Southern Mallee | Julie Gillin | 5440 6500 | JGillin@bendigohealth.org.au |
| | | | |
| North-east Hume | Susan McLees<br>Jo Freudenstein<br>Megan Hollingworth | 02 6024 7711 | Susan.McLees@wrhs.org.au<br>joanna.freudenstein@awh.org.au<br>megan.hollingworth@awh.org.au |
| | | | |
| Goulburn & Southern | Susan Galambos | 5832 2160 | susan.galambos@gvhealth.org.au |
| | | | |
| Northern Mallee | Mirabel McConchie | 5022 3500 | mcconchiem@ramsayhealth.com.au |

- Child and Adolescent Mental Health Services (CAMHS/CYMHS)

http://www.health.vic.gov.au/mentalhealth/camhs/

As a tertiary level service, the CAMHS/CYMHS typically see children with more complex, high risk or crisis level needs. CAMHS/CYMHS are not able to meet the demand of ASD assessments alone and work carefully with partners in the private and public sector to meet the shared obligation of assessment and treatment for children and families. CAMHS/CYMHS ASDs coordinators support community partners in their work where possible, and confer on or assess the most complex cases. They serve as an important hub of expertise in ASD assessment and treatment and further support clinicians in their region with professional development and secondary consultation.

The regional CAMHS/CYMHS ASD coordinators are supported by a dedicated state-wide ASDs coordinator located at Mindful: Centre for Training and Research in Developmental Health, University of Melbourne. A training program in assessment, diagnosis and treatment for Paediatric fellows, Psychiatric registrars and mental health clinicians has also been funded by the Department of Health and designed and delivered by Mindful: Centre for Training and Research in Developmental Health, University of Melbourne. Regular training is provided on the fundamental of ASDs assessment and diagnosis and is enhanced by follow-up seminars on assessment and treatment for adolescents and young adults, and workshops on specific assessment instruments (e.g. ADOS, PEP-3).

- Mindful: Centre for Training and Research in Developmental Health

http://www.mindful.org.au/

Other assessment information:

The ‘Raising Children Network’ website has an interactive Autism Service Pathfinder to assist parents and professionals in finding and accessing available services and resources throughout Australia. The pathfinder begins with parent and professional first concerns about a child’s behaviour and development and provides flowchart for assessment services and support

http://raisingchildren.net.au/services_pathfinder/services_pathfinder.html

# Intervention & treatment (Childhood)

As the aetiology of ASDs has not yet been determined in the majority of cases, there is no specific treatment for these complex neuro-developmental conditions. Conflicting opinions over treatment methods continue while researchers attempt to identify what kinds of interventions are most efficacious, the degree of improvements that can be expected, which variables mediate treatment gains and if an intervention focussing on one aspect of autism results in concurrent improvements in other areas. Francis (2005) stated that, as there is "…no cure at present, the word "treatment" should only be used in a very limited sense, reflecting interventions aimed at helping people with ASD to adjust more effectively to their environment" (p. 493).

Volkmar et al. (2004) commented that "a major concern is the large, and possibly growing, gap between what science can show is effective, on the one hand, and what treatments parents actually pursue" (p. 155). A clinical report of the American Academy of Pediatrics (Myers & Johnson, 2007) discussed the common use of complementary and alternative medicines for the treatment of young children with ASDs which lack empirically validated research. The report stated that:

> "…families are often exposed to unsubstantiated, pseudoscientific theories and related clinical practices that are, at best, ineffective and, at worst, compete with validated treatments or lead to physical, emotional or financial harm. Time, effort, and financial resources expended on ineffective therapies can create an additional burden on families" (p. 1174).

## Helpful questions for parents

Will the treatment result in harm to my child? (physical or psychological harm)

Is the treatment developmentally appropriate for my child?

How will failure of the treatment affect my child and family?

Has the treatment been validated scientifically?

How will the treatment be integrated in to my child's current program? Freeman (1997)

## Best practice guidelines

Several studies and reports on evidence based treatments and interventions for primary school aged children have been published over the past decade. These papers provide important information for parents and professionals to assist them in making informed decisions about educational interventions.

Iovannone, Dunlap, Huber & Kinkaid (2003) were interested in determining if the core elements of effective educational programs identified in reports on young children with an ASD were consistent with practices for older children. In their paper on effective educational placements for students with an ASD (at least 5 years of age) they listed six core elements of educational practice with empirical support.

The core elements included:

- the provision of individualised supports and services for students and families
- systematic instruction, comprehensive and structured learning environments
- specialised curriculum content
- a functional approach to difficult behaviours
- family involvement

i) A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders (*0-7 years*)

An Australian report 'A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders' (Prior, Roberts, Rodger, Williams & Sutherland, 2011) provides a review of the research literature relating to the management and treatment of young children with ASDs to identify the most effective models of best practice. In particular, the report outlines the treatments which are eligible to be funded through the federal government's Helping Children with Autism (HCWA) funding. The funded interventions have good scientific and clinical merits which are likely to contribute to improved outcomes for children (0-7 years) with an ASD and their families.

http://www.fahcsia.gov.au/

ii) The 'Raising Children Network'

The parent guide to therapies offers reliable information about a wide range of therapies and interventions for children with ASD. Each guide gives an overview of the therapy, what research says about the therapy and the approximate time and costs involved

http://raisingchildren.net.au/parents_guide_to_therapies/parents_guide_to_therapies.html

iii) The National Standards Reports

A report from the National Autism Centre (2009) in the USA provided information about the level of scientific evidence that existed in support of educational and behavioural treatments for individuals (0-22 years) with an ASD in the National Standards Report. The report used four levels of strength of evidence (established, emerging, unestablished and ineffective) and was the first to have also provided information about treatment effectiveness based on age, diagnostic group and treatment targets. The National Autism Centre's Standards Report (2009) recommended that parent-professional teams give serious consideration to 'established' treatments, do not begin with 'emerging' treatments, and only consider 'unestablished' treatments after additional research has been conducted and shown favourable outcomes.

Eleven 'established' treatments were identified, of which ten were recognised for children between the ages of 6-9 years. These included:

- antecedent package
- behavioural package
- comprehensive behavioural treatment
- modelling
- naturalistic teaching strategies
- peer training package
- pivotal response treatment
- schedules
- self-management
- story-based interventions

Seven ‘established’ treatments were identified for children between the ages of 10-14 years. These included:

- antecedent package
- behavioural package
- modelling
- peer training
- schedules
- self-management
- story-based interventions

The National Standards Report also identified many ‘emerging’ treatments for school-aged children and stated that:

> “Given the limited research support for Emerging Treatments, we generally do not recommend *beginning* with these treatments. However, Emerging Treatments should be considered promising and warrant serious consideration if established treatments are deemed inappropriate by the decision-making team” (p. 76).

Fifteen ‘emerging’ treatments were identified for children between the ages of 6-14 years which included:

- augmentative and alternative communication
- cognitive behavioural intervention package
- exercise
- imitation based interventions
- initiation training
- language training
- multi component
- picture exchange communication system
- scripting
- sign instruction
- social skills package
- structured teaching
- peer mediated instructional arrangement
- technology-based treatment
- theory of mind training

It is of equal importance for us to be informed about those treatments that are identified as ‘unestablished’. Unestablished treatments are described as those for which there is little or no evidence in the scientific literature to draw firm conclusions about the effectiveness of these interventions with individuals with ASD. The NAC guidelines state that “There is no reason to assume these treatments are effective. Further, there is no way to rule out the possibility these treatments are ineffective or harmful” (p. 70). This is because the quality, quantity, and consistency of research findings have generally been poor or do not apply to individuals with ASD.

The following treatments have been identified as having  unestablished level of evidence:

- academic Interventions
- auditory integration training
- facilitated communication
- gluten- and casein-free diet
- sensory integrative package

Furthermore, the NAC guidelines state that:
“There are likely many more treatments that fall into this category. That is, there are many treatments for which no research has been conducted or, if studies have been published, the accepted process for publishing scientific work was not followed. There are a growing number of treatments that have not yet been investigated scientifically. These would all be Unestablished Treatments. Further, any treatments for which studies were published exclusively in non-peer-reviewed journals would be Unestablished” (p.70).

- Further details of each of these interventions can be obtained by reading the report.

http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf

More recently, the NAC published two further reports.

- ‘Evidence-based practice and autism in the schools:  A guide to providing appropriate interventions to students with ASDs’ (2011). This manual is a valuable guide for teachers that provides an outline of ASDs summarises the research findings from the previous NAC report, describes the importance of professional judgment, and the values and preferences of families in evidence based practice.

- ‘Evidence-based practice and autism; providing information and resources for families of children with ASDs’ (2011). This manual begins with a review of the ASDs and describes effective treatments. Other topics include the importance of professional judgment, the role of family preferences and values in the decision-making process, and factors to consider when choosing a team of professionals. The manual was co-authored by professionals and parents of children with an ASD.

http://www.nationalautismcenter.org/index.php

## Educational supports and services in Victoria

- ASD coaches (DEECD)

In 2012, the Commonwealth and Victorian state governments developed a range of strategies under the 'More Support for Students with Disabilities National Partnership' to ensure better support for students with a disability. Part of this initiative was the recruitment of regional ASD coaches.

DEECD ASD Coaches

| **New Region** | **Former Region** | **Name** | **Contact Details** |
|---|---|---|---|
| North-Eastern-Victoria | Eastern Metro<br>Hume | Heather Mosley<br>Sue Alexander | mosley.heather.e@edumail.vic.gov.au<br>alexander.susan.s@edumail.vic.gov.au |
| | | | |
| North-Western Victoria | Loddon Mallee<br>Northern Metro | Paul Keller<br>David Ward | keller.paul.j@edumail.vic.gov.au<br>ward.david.j@edumail.vic.gov.au |
| | | | |
| South-Eastern Victoria | Gippsland<br>Southern Metro | Wendy Holcombe<br>Cecelia Morales | holcombe.wendy.m@edumail.vic.gov.au<br>morales.cecilia.a@edumail.vic.gov.au |
| | | | |
| South-Western Victoria | Barwon South West<br>Grampians<br>Western Metro | Sally Midwood<br>Chris Grigg<br>Michelle Savage | midwood.sally.s@edumail.vic.gov.au<br>grigg.chris.c@edumail.vic.gov.au<br>savage.michelle.m@edumail.vic.gov.au |

- Autism Friendly Learning website

DEECD is working to build the skills and resources of all Victorian government schools and early childhood settings to provide an ASD friendly learning environment.

http://www.education.vic.gov.au/about/directions/autism/default.htm

- Positive Education Planning

The Association for Children with a Disability (ACD) has developed a booklet about positive education planning for students with a disability attending Victorian government primary schools.

http://www.acd.org.au/information/indexb.htm

- Evidence-based practice and autism in the schools (NAC, 2011)

This manual is a valuable guide for teachers that provides an outline of ASDs, summarises the research findings from the previous NAC report, describes the importance of professional judgment, and the values and preferences of families in evidence based practice.

http://www.nationalautismcenter.org/index.php

- Helping Children with Autism (HCWA)

Amaze (Autism Victoria)administers federal government funding which is available in Victoria through the Autism Advisor Program.  A team of Autism Advisors provide help with the funding program and a bi-monthly newsletter which provides updates on the program. Funding of up to $12,000 (maximum of $6,000 per financial year) can be accessed until the child's seventh birthday.

http://www.amaze.org.au/discover/how-we-can-help-you/hcwa/

- Disability Services (DHS) ph. 1800783783

The department funds a range of specialist disability supports that are available to people with a disability, including those with an ASD, and their families. These are short-term supports (respite services, behaviour supports, case management and therapy) and ongoing supports (individual support packages and shared supported accommodation).
The Intake and Response Service provides information about supports and services for people with disabilities, their families and carers in their local area.

http://www.dhs.vic.gov.au/home

- Allied Health Practitioners

Allied health practitioners can provide a range of interventions for school-aged children. Therapists typically work within a local community health centre or through a private practice. They are sometimes available to provide support and consultation to the child's school and attend SSGs. Professional organisations have online lists of registered therapists

Australian Psychological Society

http://www.psychology.org.au/findapsychologist/

Occupational Therapy Australia

http://www.otaus.com.au/findanot

Speech Pathology Australia

http://www.speechpathologyaustralia.org.au/about-spa/find-a-speech-pathologist

## Schooling options

There are a range of schooling options for children in the primary school years which provides parents with important, and sometimes difficult, decisions. Advice from professionals, family and friends can sometimes be conflicting or inaccurate. Mostly, parents want their child to be welcomed and valued by the school community, for their child to have the best possible start in their formal education and to reach their potential. They want their child to be happy and have friends.

The following describes the schooling options for Victorian primary school aged children.

### i) State government schools (DEECD)

State government schools include local primary schools, autism specific schools, specialist schools (SS) and special developmental schools (SDS). Some children enrol at both the local primary and specialist school (dual enrolment). Some government schools have a ‘base room’ or ‘satellite unit’ to cater for students with an ASD.

Three levels of support is provided for students with an ASD by DEECD including:

a. A whole school approach to building a positive school culture

A range of resources may be provided via the Student Resource Package, through specific early identification and intervention programs, or through student support services. The student support services officer (SSSO) program provides specialised support to children and young people with additional needs or at risk of disengagement and their families, and to strengthen the capacity of schools to engage all students in education. SSSOs include psychologists, guidance officers, speech pathologists, social workers, visiting teachers and other related professionals.

http://www.education.vic.gov.au/healthwellbeing/support/ssso.htm

b. A targeted approach to identify and address need

This may include establishing a Student Support Group (SSG) and an Individual Learning Plan (ILP) developed for each student. A Student Support Group is a partnership involving parents, school representatives and professionals to develop coordinated support for the student through the development of specific educational goals strategies.

c. An intensive response to address need.

The Program for Students with Disabilities (PSD) is an intensive program for eligible students. The Program supports the education of students with disabilities in Victorian government schools by providing schools with additional resources. The PSD is available for eligible students with critical educational needs in the categories of physical disability, visual impairment, severe behaviour disorder, hearing impairment, intellectual disability, ASDs and severe language disorder.

http://www.education.vic.gov.au/healthwellbeing/wellbeing/disability/handbook/default.htm

In 2012, the Commonwealth and Victorian state governments developed a range of strategies under the ‘More Support for Students with Disabilities National Partnership’ to ensure better support for students with a disability. The partnership initiatives target four key areas: building school capacity, strengthening options, utilizing technology and a focus on teaching and learning (DEECD, 2012).

Strategies include:

- Autism teacher coaches and school support in each region
- Autism inclusion support coordinators
- Autism teacher specialisation scholarships
- Expert consultation for ASD through Autism Victoria (amaze)
- Inclusion Online professionals learning portal
- Disability standards for education – professional learning for schools

http://www.education.vic.gov.au/healthwellbeing/wellbeing/mssd.htm

### ii) Catholic Schools

The Catholic Education Office provides assessment services and student learning program support, as well as assistance for schools in devising and implementing Individual Learning Plans (ILP) for students with additional learning needs, including those with an ASD. The criteria for eligibility of funding for students with an ASD attending a catholic school are similar to that used in government schools; however the amount of funding allocated may be less. The Australian Catholic University also provides services including counselling and educational assessments through the Melbourne Psychology and Counselling Clinic .

http://www.ceo.melb.catholic.edu.au/

### iii) Independent schools

There are many independent schools throughout Victoria including specialist schools for students with learning difficulties (e.g. SDS) and for students with an ASD (e.g. Mansfield Autism Statewide Services schools). Other independent schools offer educational programs based on the approaches of Montessori or Steiner, whilst others are denominational. Independent schools Victoria provides a handbook outlining support for students with a disability which includes Disability standards for education and guidelines for Program Support Groups (PSG).

Australian Government targeted funding for eligible students with disabilities (including ASDs) in independent schools is available through the ‘Literacy, Numeracy and Special Learning Needs Program’. Victorian Government targeted funding for eligible students are available through the ‘State Support Services Program’. The criteria for eligibility of funding for students with an ASD attending an independent school are similar to that used in government schools; however the amount of funding allocated may be less.

- Association of Independent Schools, Victoria

http://www.independentschools.vic.edu.au/

### iv) Home schooling

Home schooling is a recognised alternative to attending government or registered non-government schools. That involves parent/s taking responsibility for the planning, implementation and assessment of their child's education.

Parents interested in home schooling must register with the Victorian Registration and Qualifications Authority (VRQA), a statutory authority responsible for the registration and accreditation of education and training providers. The *Education and Training Reform Act* 2006 requires that all children of compulsory school age (6 to 17 years) are enrolled in a school, or registered for home schooling.

- Home schooling in Victoria: A guide to services and support (DEECD, 2010)

http://www.eduweb.vic.gov.au/edulibrary/public/commrel/aboutschool/homeschoolingbooklet.pdf

## The Student Support Group and Individual Learning Plan

A Student Support Group (SSG) should be available whether a student with an ASD attends a government, independent or catholic school, and also whether they are eligible for additional integration funding or not. Members of the SSG may include the parent/s, class teacher, principal (or nominee), parent advocate, the student (where appropriate) and professional consultants.

The aims of a Student Support Group are generally to:

- Ensure that parents and professionals (and the student where appropriate) work together to share information
- Identify needs and establish shared goals and strategies
- Provide ongoing educational planning and monitoring of the student's progress
- Plan and implement appropriate support for the student, parents and teaching team

The aims of an Individual Learning Plan (ILP) are generally to:

- Identify needs and establish shared goals and strategies
- Provide ongoing educational planning
- Evaluate and monitor the student's progress
- Determine adjustments that need to be made to the environment, curriculum…

## Transition to school

As yet there is no literature on evidence-based management of transition to school for children with an ASD. As children move beyond the safety, routine and predictability of the family and early childhood settings, they enter a much larger and diverse school community. Starting school is an exciting step, but it can also be a difficult time for children with an ASD and their parents. The transition usually involves extra challenges and may be a source of stress and anxiety for parents, professionals and the child. This may also be the case for those students with an ASD making the transition from one grade to the next or from primary school to secondary school. Successful transition requires careful planning, preparation and communication that lead to a shared understanding of each student. In Victoria, there are a number of supports and training opportunities to encourage a planned approach to transitions.

- A Positive Start to School (DEECD)

. The 'Positive Start to School' aims to develop a shared understanding between families, early childhood services and schools about what is important for children and their families. It includes the completion of a 'Transition Learning and Development Statement' to enable the transfer of information from early childhood and care to primary school.

http://www.education.vic.gov.au/earlylearning/transitionschool/about.htm

- ASD: Planning a successful transition to primary school (Brereton & Bull, 2012)

The 'Autism Spectrum Disorders: Planning a successful transition to primary school' program has been developed to complement the 'Positive Start to School' initiative. This program provides local workshops for parents and educators to attend together to develop a relationship and shared understanding prior to the child's school commencement. Together, they complete an 'ASD transition learning and development statement' as part of a planned approach to transition. Factsheets and 'ASDs transition learning and development statements' are also available on the DEECD autism friendly learning website.

http://www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx

- ASDs: Planning a successful transition to secondary school (Brereton & Bull, 2012)

This program was developed to support parents and professionals working in primary schools, specialist schools and secondary schools. Like the transition to primary school program, it is not intended to be a "crash course" in ASDs. Instead, the focus is on creating an effective transition team and working together to develop a transition plan. The ½ day workshop for the transition team provides an overview of ASDs and how they affect young people’s thinking and learning, communication, social relating skills, emotions, behaviour, and mental health. The program equips staff and families with relevant and useful resources to assist in the transition planning. Factsheets and ‘ASDs transition learning and development statements’ are also available. Workshops are facilitated throughout Victoria by DEECD SSSOs and ASD Coaches.

http://www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx

## Family information, education & support

Some parents report that they felt a decrease in the level of support and services they had received as their child moved from early childhood services to school. Some parents who had previously enjoyed regular contact with a key worker through ECIS miss that continuity of care during their child's primary school years. Other parents miss the informal daily contact they had with their child's kindergarten teacher. Other's find that the level of therapy services decrease as their child spends a full day at school. Successful programs provide support for parents, as well as the child with an ASD, during the transition from one service to another with the knowledge that some families experience additional stress at this time.

A common recommendation from all of the ASDs best practice guidelines is that family involvement, support and education is critical (Dawson & Osterling, 1997; Francis, 2005; Howlin, 1998; Jordan et al., 1998; Kanthor et al., 1999; Le Couteur, 2003; National Research Council, 2001; National Autism Centre, 2009; Osbourn & Scott, 2004; Perry & Condillac, 2003; Rogers & Vismara, 2008; Simpson, 2005). In addition, a key component of family centred practice includes sharing information so that parents can make informed decisions (Dempsey & Keen, 2008; Dunst, 2002; Espe-Sherwindt, 2008; Gabovitch & Curtin, 2009; Shelton & Stepanek, 1994). Parent education programs can lead to positive child and parent outcomes (Schultz, Schmidt & Stitchter, 2011). There is empirical evidence that ASDs specific parent education and training programs contribute to the management of behavioural problems (Sofronoff & Farbotko, 2002; Whittingham, Sofronoff, Sheffield & Sanders, 2009) and improvement in functional communication in children with an ASD (Koegel, Symon & Koegel, 2002; McConachie, Randle, Hammal & LeCouteur, 2005; Moes and Frea, 2002). Studies have also reported positive effects of education programs in parents of children with an ASD on parental mental health and adjustment and self-efficacy (Bristol & Schopler, 1983; Bristol, 1984; Sofronoff & Farbotko, 2002; Tonge et al., 2006).

There are a number of resources developed specifically for parents of school aged children with an ASD listed below.

- The ‘Raising Children Network’

A website designed to assist parents and professionals in finding and accessing available services and resources throughout Australia.
http://raisingchildren.net.au/children_with_autism/children_with_autism_landing.html/highlight/autism

- Amaze (Autism Victoria) ph. 1300308699

Information pack

A package that provides basic information about ASDs including parents’ perspectives, frequently asked questions, funding options and resources

http://www.amaze.org.au/uploads/2011/08/Information-Pack-Aug-11.pdf

Directory of autism services

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

Family counsellors

Amaze (Autism Victoria)provides telephone or face to face family counselling.

- Evidence-based practice and autism; providing information and resources for families of children with ASDs (NAC, 2011).

This manual was co-authored by parents of children with an ASD and professionals. It begins with a review of the ASDs and describes effective treatments. Other topics include the importance of professional judgment, the role of family preferences and values in the decision-making process, and factors to consider when choosing a team of professionals.

http://www.nationalautismcenter.org/index.php

- Positive Partnerships

The ‘Positive Partnerships’ project is coordinated by Australian Autism Education and Training Consortium (AAETC). ‘Positive Partnerships’ provides workshops and information sessions for parents and carers of school aged children with an ASD and incorporates an Online Learning Portal with learning modules, resources, fact sheets, workshop content and support material.

http://www.autismtraining.com.au

- ‘Through the Maze’ directory of disability services

The Association for Children with a Disability (ACD) has a comprehensive booklet titled ‘Through the Maze’ which outlines services and resources in Victoria for parent and children 0-18 years (translations available in community languages). Regional quick guides are also available.

http://www.acd.org.au/information/keycontactb.htm

- Parent Support Workers ph. 1800654013

Available through the Association for Children with a Disability (ACD) , parent support workers provide support by listening, understanding (they are themselves parents of children with a disability) and providing information and advice.

http://www.acd.org.au/support/indexb.htm

- Support groups

ASDs specific Parent-to-parent support groups are held throughout metropolitan Melbourne and in rural centres. Groups specifically for fathers, siblings, grandparents and cultural groups are also available. Amaze (Autism Victoria)has a comprehensive list of these groups available on their website.

http://www.amaze.org.au/uploads/2011/08/Victorian-Parent-Support-Groups-Sep-20111.pdf

- Translating and Interpreting Services (TIS) ph. 131450

The Commonwealth Department of Immigration and Citizenship (DIAC) provide a Translating and Interpreting Services (TIS). TIS National provides a 24-hour, 7-days a week service for individuals and organisation (costs associated). It provides immediate telephone interpreting services, as well as pre-booked telephone and on-site interpreting.

http://www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/

- Autism Spectrum Australia (Aspect)

Autism Spectrum Australia (Aspect) provides a Positive Behaviour Support Program for children and young people (aged 6-25 years) with an ASD. The programme offers three levels of support.

1. Parents can access free Positive Behaviour workshops designed to support and assist families, carers and others to develop a greater understanding of the individual with ASD and the impact that this has upon learning, behaviour and development, and to design and implement an individualised support plan based upon an identified behaviour of concern.
2. Families of clients who require support at a more intensive level can participate in these Positive Behaviour Workshops, but, in addition, will be able to apply to receive individualised support to define specific goals and to design and implement a detailed behaviour support plan in the home and in other settings (including schools). Additional training and support will be provided to local services.
3. The highest intensity of support is longer term and designed to address issues with people who have more complex needs and enduring challenges. Clients requiring this level of support may be at significant risk of family breakdown or loss of school placement.

http://www.autismspectrum.org.au

- Helping You and Your Family (Association for Children with a Disability)

‘Helping You and Your Family’ provides information, support and advocacy for parents and children of children with a disability in Victoria. The booklet is available in several community languages and is free for families.

http://www.acd.org.au/information/helpb.htm

- The Australian Advisory Board on Autism Spectrum Disorders

The Australian Advisory Board on ASDs is the national peak body representing people who have an autism spectrum disorder, their families, carers and helpers. The focus of the Advisory Board is working with governments to develop appropriate policies for people who have an ASD, their families and carers, disseminating information about ASDs and working with the Australian ASD community to build skills.

http://www.autismadvisoryboard.org.au/

## Respite

At times parents may require respite and a break from the challenging demands of caring for their child with an ASD. Extended family members such as grandparents are sometimes able to assist with caring for a child for a few hours, overnight or a weekend. This is important as parents may need time out to look after their own needs and to care for their own physical and mental health to enable them to provide optimum care for their child. Not all families have extended family support; however, there are programmes that provide respite services for families of children with a developmental disability.

Respite support is when parents/carers can take a short-term or time-limited break while someone else supports the person with a disability. Respite services aim to provide a positive experience for both the person with a disability and the parent/carer. Respite support can include community participation, in-home support or out of home support.

- Respite Victoria

Respite Victoria has been established as part of the Victorian Department of Human Service's initiatives to improve access to information about respite for carers and people with a disability in Victoria. Respite Victoria has links to the 8 regional disability respite websites in Victoria. Each regional website links you to the Respite Service Search (local and state-wide), and has specific local information, news and events.

http://www.respitevictoria.org.au/what-respite

- Carers Victoria

Carers Victoria work closely with government and other support organisations to improve the lives of caring families throughout Victoria.

http://www.carersvictoria.org.au/

## Sibling support

The sibling relationship lasts longer than all other human relationships and is the focus of research interest in the general population, as well as when a sibling has a developmental disability such as an ASD. The research findings on the impact of having a sibling with an ASD vary considerably. This may be due to the lack of consistency in research measures, with some studies using parent report, others using self-report, and most using a single type of respondent (Macks & Reeve, 2007).

Some studies have found that the presence of a sibling with an ASD may not be considered a risk-factor for adjustment problems among typically developing siblings (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2011). Other studies have suggested that siblings of individuals with an ASD and may even have enhanced psychosocial and emotional development (Kaminsky & Dewey, 2001; Macks & Reeve, 2007). However, other studies report that siblings experience higher levels of internalising behavioural problems and lower levels of prosocial behaviour when compared to siblings of typically developing children or those with other developmental problems (Hastings, 2003; Ross & Cuskelly, 2006) with an increasingly unfavourable impact on the non-disabled sibling as demographic risk factors, such as socio-economic status or number of siblings increased (Macks & Reeve, 2007) also reported. They also suggested that parents have markedly different views from the non-disabled sibling regarding the ways in which siblings' psychosocial and emotional adjustment are affected by the children with autism (Macks & Reeve, 2007). Petalas, Hastings, Nash, Lloyd and Dowey (2009) concurred with earlier studies in their findings that siblings of children with autism had an increased risk of emotional problems, and they also found that these problems persisted over time.

While the findings on the impact of having a sibling with an ASD are inconsistent, what is clear is that siblings are known to have a substantially elevated risk of also having a diagnosis, with evidence of cases of autistic disorder among siblings ranging from 2-6% (Newschaffer et al., 2002). Recent data from prospective studies of developmental trajectories of very young siblings of children with autism indicate strong evidence of early difficulties in cognitive and language development and in social engagement (Elsabbagh & Johnson, 2007; Gamliel, Yirmiya, Jaffe, Manor & Sigman, 2009; Orsmond & Seltzer, 2007; Yirmiya & Ozonoff, 2007).

Sibling relationships change over time in the general population as each sibling moves through different life stages. The symptoms of ASDs also change over time, which may have further implications on the sibling relationship. Clearly, the needs of siblings must be considered in intervention programmes. Siblings need developmentally appropriate information and support. There are siblings support groups and information available through local and state-wide services, including online social-networking sites.

- Association for Children with a Disability

Provides a range of factsheets, booklets and access to local sibling support programmes.

http://www.acd.org.au/siblings/indexb.htm

- Sisters Individuals Brothers (SIBS)

Information and resources for primary school aged and adolescents with a brother or sister with a disability or chronic illness.

www.sibs.org.au

- The Royal Australian and New Zealand College of Psychiatrists (RANZCP)

The Royal Australian and New Zealand College of Psychiatrists (RANZCP), through the work of its Faculty of Child and Adolescent Psychiatry (FCAP), has recently published a position statement: Addressing the needs of siblings of children with disability or chronic illness.

http://www.ranzcp.org/policy-advocacy/addressing-the-needs-of-siblings-of-children-with-disability-or-chronic-illness.html

## Financial Support

Families of children with an ASD are reported to have greater financial burden compared with other children with special health care needs (Jabrink, Fombonne & Knapp, 2003; Kogan et al., 2008). In particular, Kogan et al. (2008) found that parents report the need for additional income for their child's care and are more likely than parents of children with other health care needs to reduce or stop work due to their child's disability. Parent/carers of a child with an ASD can access financial support through:

- The Carer Allowance (Centrelink) ph: 13 27 17

The Carer Allowance not means tested) assists parents of a child with a disability financially and can be applied for through Centrelink. Children with the diagnoses of Asperger Syndrome and Autism are recognised disabilities indicating eligibility and no requirement for further medical assessment until the child's 16th birthday. The Carer Allowance *Medical Report* can be completed by a range of health professionals.

http://ww.centrelink.gov.au/internet/internet.nsf/forms/ci002.htm

- Chronic Disease Management Plan (Medicare)

The Chronic Disease Management Plan (CDMP) provides five sessions with an allied health professional per calendar year and funding for dental treatment. The CDM plan can be written by a GP.
http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement

- Mental Health Care Plan (Medicare)

Medicare rebate through a Mental Health Care Plan provides six sessions with an allied health professional. An additional four session may also be available in exceptional circumstances. Ten group sessions with an allied health professional are also available. This is available for the individual with an ASD, parents, siblings and carers who may need help with their mental health and wellbeing.

http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-b-better

- Assessment (Medicare)

Medicare rebate through 'Helping children with Autism' is available for four appointments for assessment with a private practitioner/s are available. Practitioners may include a paediatrician, psychiatrist, psychologist, speech pathologist, occupational therapist, audiologist, optometrist, audiologist, orthoptist or physiotherapist.

- Helping Children with Autism Treatment (Medicare)

Medicare rebate is available for 20 sessions with an allied health practitioner following a diagnosis of a PDD. The plan must be written by the child's 13th birthday and used by their 15th birthday.

http://www.fahcsia.gov.au/sa/disability/progserv/people/HelpingChildrenWithAutism/Pages/default.aspx

- Amaze (Autism Victoria)information pack

This information package provides basic information about funding options and financial supports

http://www.amaze.org.au/uploads/2011/08/Information-Pack-Aug-11.pdf

## Professional information, education & support

There is increasing range of education and supports for professionals working in Victoria with primary school students with an ASD and their families. These include specific workshops for teachers and aides, certificate courses, scholarship programs, as well as communities of practice and on-line factsheets and resources.

- Regional Autism Consultation and Training or Regional Autism Planning Teams

Regional Autism Coordination Teams (ReACTs) or Regional Autism Planning Teams (RAPT) teams identify and respond to the ASDs training and consultation needs in their local areas. DEECD has employed nine ReACT or RAPT Coordinators.

| REGION | COORDINATORS | EMAIL |
|---|---|---|
| North | Priscilla Parodi | parodi.priscilla.p@edumail.vic.gov.au |
| South | Cecilia Morales | morales.cecilia.a@edumail.vic.gov.au |
| East | Anne Kettle | kettle.anne.t@edumail.vic.gov.au |
| West | Anne Butterworth | butterworth.anne.a@edumail.vic.gov.au |
| Hume | Jenny Drysdale | drysdale.jennifer.m@edumail.vic.gov.au |
| Grampians | Desley Beechley | beechey.desley.j@edumail.vic.gov.au |
| Loddon-Mallee | Angela Walsh-Edgar | walsh-edgar.angela.t@edumail.vic.gov.au |
| Gippsland | Naomi Licciardello | Licciardello.naomi.w@edumail.vic.gov.au |
| Barwon South-West | Jann Kirkland | Kirkland.jann.e@edumail.vic.gov.au |

- Autism Teaching Institute (ATI)

In 2006, DEECD established the Autism Teaching Institute (ATI) based at Western Autistic School. The ATI provides accredited training courses and professional development opportunities to build teacher and allied health skills and knowledge about students with an ASD.

http://www.autismteachinginstitute.org.au/

- Communities of Practice (Disability Services)

Case Consultation Practitioners are employed by DHS in each region across Victoria. They are responsible for providing secondary consultation to disability case managers and developing or building on existing local networks to enhance linkages and pathways.

They have also created 'communities of practice' to provide a means of continual learning and development for disability services staff. Case consultant practitioners are based at various organisations across Victoria.

| REGION | ORGANISATION | EMAIL |
|---|---|---|
| **North/West** | Autism Vic. | www.amaze.org.au/learning |
| **South** | Windermere | www.windermere.org.au |
| **East** | Autism Vic. | www.amaze.org.au/learning |
| **Hume** | Mansfield Autism Statewide Services | www.autismmansfield.org.au |
| **Loddon-Mallee** | Community Living & Respite Services Inc. | www.clrasd.org.au |
| **Gippsland** | SCOPE | https://sites.google.com/site/autismgippsland/ |
| **Barwon S-W** | Gateways<br>MPOWER | www.gateways.com.au<br>www.mpower.org.au |

- Training for integration aides in schools

The Autism Teaching Institute (ATI) has been engaged by DEECD to facilitate educational workshops. 'Window into Autism' is a professional learning opportunity for integration aides who want to understand more about ASDs and improve outcomes for the students.

http://www.education.vic.gov.au/proflearning/sso/asd.htm

- Teacher scholarships

The Special Education Scholarship scheme supports current teachers in Victoria seeking to complete an endorsed special education qualification, including specialist areas such as ASDs.

http://www.education.vic.gov.au/hrweb/careers/teach/scholarships.htm

- Autism Spectrum Australia (Aspect)

Autism Spectrum Australia (Aspect) provides a Positive Behaviour Support Program for children and young people (aged 6-25 years) with an ASD. The programme offers three levels of support.

1. Parents can access free Positive Behaviour workshops designed to support and assist families, carers and others to develop a greater understanding of the individual with ASD and the impact that this has upon learning, behaviour and development, and to design and implement an individualised positive behaviour support plan based upon an identified behaviour of concern.

2. Families of clients who require support at a more intensive level can participate in these Positive Behaviour Workshops, but, in addition, will be able to apply to receive individualised support to define specific goals and to design and implement a detailed behaviour support plan in the home and in other settings (including schools). Additional training and support will be provided to local services.

3. The highest intensity of support is longer term and designed to address issues with people who have more complex needs and enduring challenges. Clients requiring this level of support may be at significant risk of family breakdown or loss of school placement.

http://www.autismspectrum.org.au

- Positive Partnerships

The ‘Positive Partnerships’ project is coordinated by Australian Autism Education and Training Consortium (AAETC). ‘Positive Partnerships’ provides professional development for teachers and other school staff who are working with students with an ASD. Workshops incorporate an Online Learning Portal where teachers can access learning modules, resources, fact sheets, workshop content and support material.

http://www.autismtraining.com.au/public/index.cfm?action=showPublicContent&assetCategoryId=686

- Amaze (Autism Victoria)workshops, courses and information

Providing training workshops, courses, information sessions and other training opportunities is one of the primary activities of amaze. Amaze Knowledge delivers a range of structured and personalized education courses for services and organizations directly involved in supporting individuals and families with an ASD. They also have a certified training course and arrange national and international speakers for conferences and special events.

http://www.amaze.org.au/discover/how-we-can-help-you/learning-education/

- Evidence-based practice and autism in the schools: A guide to providing appropriate interventions to students with ASDs' (2011).

This manual is a valuable guide for teachers that provides an outline of ASDs, summarises the research findings from the national standards report, describes the importance of professional judgment, and the values and preferences of families in evidence based practice.

http://www.nationalautismcenter.org/index.php

- Inclusion Online course: Understanding Autistic Spectrum Disorder

The *Inclusion Online* courses are an online learning portal that are available across Victorian government schools, and free to all teachers from government schools. The course is held over a ten week period requiring approximately two hours online participation per week. Course participants are supported by an online tutor and study alongside up to 12 colleagues. Although the course is delivered online, there are three one-hour face to face sessions occurring over the ten weeks.

http://www.pd-online.com.au

# Other considerations (Childhood)

All children diagnosed with autism have problems in the core areas of communication, social skills and restricted and repetitive patterns of play and behaviour, Some children with an ASD also have associated features such as sleep problems, fussy eating, sensory disturbance or motor impairment that also occur in children with other developmental problems and are not specific to children with an ASD.

## Associated features of ASDs

### Motor impairment

Delayed motor milestones, clumsiness, poor co-ordination, impaired postural control, awkward gait and motor planning problems are common in children with an ASD (Ghaziuddin, Butler, Tsai & Ghaziuddin, 1994; Green et al., 2002; Ming, Brimacombe & Wagner, 2007; Mostofsky, Burgess, & Gidley Larson, 2007; Rinehart et al., 2001; Rinehart et al., 2006). Van Waelvelde (2010) has also reported consistency of poor motor performance in children with autism over time. These range of motor problems become increasingly evident in the primary school years as children have difficulty with handwriting and sport programs.

### Sleep problems

Reports of sleep problems in children with an ASD range from 40% - 80% compared to 30% for typically developing children (Goodlin-Jones et al., 2009). Parents of children with an ASD commonly report problems with their child going to bed, falling asleep and waking frequently, which are associated with disruptive daytime behaviour and increased family stress (Richdale, Francis, Gavidia-Payne & Cotton, 2000). Although parent reports support the persistence of sleep problems through their child's primary school years, there have been relatively few empirical studies (Goodlin-Jones et al., 2009).

## Fussy eating

Children with autism exhibit more eating and meal-time problems and eat fewer foods from each food group (fruits, dairy, vegetables, proteins, starches), than typically developing children (Schreck et al., 2004). The range of concerns described by parents and reported in the literature generally relate to food/liquid selectivity based on presentation or type, food refusal, and concerns about unusual mealtime behaviours, such as sniffing or inspecting foods, gorging, hording or gagging. Parents often report that the concerns they had about their child's fussy eating in the early years has decreased over time. This may reflect a decrease in parental worry as they observe their child grow and develop despite a limited diet, rather than an increase the range of food they eat.

## Sensory disturbance

Sensory problems are often associated with ASDs, but may also occur in children with other developmental problems and are not specific to children with an ASD. Sensory problems are described as contributing to high levels of distress, fear and anxiety, which disrupt daily life and social functioning, but also as a source of pleasure and safety (O'Neill & Jones, 1997). Research studies on sensory problems for individuals with autism are limited compared to studies of other aspects of development and often suffer from methodological limitations. However, empirical studies suggest that sensory problems are present in most children with autism and they manifest very early in development (Baranek, 2002).

The criteria for the proposed DSM-V includes a new category of hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (APA, 2011).

## Associated conditions

### Intellectual disability

Very often, children previously diagnosed with an ASD will have a formal cognitive assessment prior to attending primary school. The majority of children with autism have an intellectual disability (Volkmar & Klin, 2005) with approximately 20-30% scoring within the normal range of intelligence, 30% score within the mild-moderate range of intellectual disability and about 40% in the severe to profound range (Fombonne, 2005). Approximately 20% of children with autism do not have an intellectual disability and are referred to as having High Functioning Autism (HFA). While children with ASD can be difficult to assess using standardised cognitive assessments, it has been found that, if appropriate tests are used, the results are valid and reliable (Clark & Rutter 1979) and are stable over time (Howlin 2005). Children with an ASD typically have an. uneven profile of abilities with deficits in verbal sequencing and abstraction skills and better rote memory skills. Tasks requiring manipulative, visuo-spatial skills or immediate memory may be performed well, such as block design and object assembly. These skills may be the basis of ‘islets of ability’ such as the musical ability shown by a few children with an ASD.

### Attention Deficit and Hyperactivity

Attention Deficit Hyperactivity Disorder (ADHD) is a childhood-onset disorder with three main subtypes; hyperactive, inattentive and mixed. (DSM-IV-TR, APA, 2000). Whilst causality is unknown, it occurs more frequently in individuals with epilepsy (Hesdorffer et al., 2004) and developmental disabilities (Ghaziuddin, 2005). DSM-IV-TR (APA, 2000) has a caveat that ADHD should not be diagnosed concurrently with autism although this is likely to be changed in DSM-V (APA, 2011). Studies indicate that co-occurrence of ADHD and autism symptoms is common, (Nick et al, 2000; Goldstein & Schwebach, 2004; Loveland & Tunali-Kotoski, 1997; Rinehart & Tonge, 2007; Rommelse, Franke, Geurts, Hartman & Buitelaar, 2010; Simonoff et. al., 2006) with at least 30% of children with an ASD experiencing significant problems with distractibility, inattention, impulsiveness, fidgetiness and motor over-activity (Goldstein & Schwebach, 2004; Reierson et al., 2007). It is anticipated that DSM-V will address this issue. ADHD symptoms, which can interfere with learning and social interactions, generally reduce as the child matures (Tonge & Rinehart, 2006). Children with a co-occurrence of ASD and ADHD symptoms may respond to behavioural and pharmacological interventions (Ghaziuddin, 2005; Reiersen & Todd, 2008).

### Epilepsy

There is a known association between autism and epilepsy with prevalence rates of epilepsy in those with autism varying from 5% - 40% compared to the general population of .5% - 1% (Amiet et al., 2008). The risk for epilepsy in autism is higher for girls and for individuals who also have an intellectual disability (Amiet, et al, 2008) and also for those who have had a traumatic birth (Larson et al., 2005).. Peak periods of seizure onset are reported to be in early childhood and adolescence (Tuchman & Rapin, 2002).

Epilepsy Foundation of Australia http://www.epinet.org.au/

## Mental health and emotional and behavioural wellbeing

Children with an ASD are at risk of significantly higher levels of emotional and behavioural problems compared to their typically developing peers, and also those with an I.D. (Bradley et al., 2004; Brereton, Tonge & Einfeld, 2006; Lainhart & Folstein, 1994; Smalley, McCracken & Tanguay, 1995; Steinhausen & Metzke, 2004). Emotional and behavioural problems (psychopathology) in toddlers, children and adolescents with ASDs has been found to contribute to maternal stress and parental mental health problems (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hastings et al., 2005; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Tonge & Einfeld, 2003). The emotional and behavioural problems most often associated with ASDs in childhood are anxiety and depression.

### Anxiety

Anxiety disorders differ from fears and worries (which are common in individuals with an ASD), in the level of severity, associated distress and life interference. Studies report high rates of anxiety disorders in individuals with an ASD (Fombonne, 1992; Gillot et al., 2001; Nick et al., 2000; Simonoff et. al., 2008). In addition to generalized anxiety disorder, individuals with an ASD can also develop distinct anxiety disorders such as obsessive compulsive disorder and post traumatic stress disorder (Ghaziuddin, 2005). Symptoms of anxiety, (e.g. fears, resistance to change, panic, phobias, tenseness, shyness, irritability and somatic symptoms) cause distress and impairment for the individual, but also have the potential to disrupt education, further impair social interaction and create management problems and stress for the parents and carers. Individuals with symptoms of anxiety may respond to cognitive and behavioural treatment approaches and also to pharmacological treatments (Tonge & Einfeld, 2003).

### Depression & other mood disorders

Mood disorders, including depression, are the most common psychiatric disorder occurring in the general population (Ghaziuddin, 2005), characterised by depressed mood, irritability, sleep and appetite disturbance, negative thoughts, lethargy and a loss of enjoyment or pleasure in normally enjoyable activities. Individuals with an ASD are at increased risk of suffering depression and mood disturbance (Bradley et al., 2004; Brereton et al., 2006; Lainhart & Folstein, 1994;

Ghaziuddin, Ghaziuddin & Greden, 2002; Sterling, Dawson, Estes & Greenson, 2008; Tonge & Einfeld, 2003) probably due to both biological and environmental factors (Brereton et al., 2006). Whilst prevalence is not known, studies suggest that it is the most common psychiatric disorder seen in individuals with an ASD, but can be difficult to diagnose in those with severe cognitive and communication impairment (Ghaziuddin, 2005). Those individuals with an ASD suffering from depression often display an exacerbation of symptoms, such as social withdrawal and an increase in obsessive compulsive behaviours. They may also display a change in character of their obsessional interests and activities, irritability, sadness, aggression or a regression in skills (Ghaziuddin, 2005). Children with autism are more likely to have a family history of depression (Ghaziuddin & Greden, 1998). In particular, mothers of children with autism are more likely to suffer from depression than mothers of children with an ID without autism and also mothers of typically developing children (Bristol, Gallagher & Holt, 1993; Olsson & Hwang, 2001; Piven & Palmer, 1999; Wolf, Noh, Fisman & Speechley, 1989; Yirmiya & Shaked, 2005). Individuals with an ASD may respond to psychological treatments such as cognitive therapy, relaxation training, and pleasant events scheduling, as well as pharmacological treatment for severe or persistent depressive symptoms.

- The Developmental Behaviour Checklist (DBC) measures emotional and behavioural problems in children with developmental disabilities. There is both a 96 item parent-completed questionnaire (DBC-P) and a teacher version of the DBC (DBC-T) which allows educators to provide valuable additional information about the child in a school setting. The DBC-P (parent) has been translated into other languages, including Arabic, Chinese, Croatian, Dutch, Finnish, French, German, Greek, Hindi, Italian, Japanese, Malay, Norwegian, Portuguese, Portuguese (Brazil), Spanish, Swedish, Turkish and Vietnamese. The DBC-T (teacher) has been translated into Spanish, Dutch, French and Finnish.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

- Child and Adolescent Mental Health Services

In Victoria, CAMHS/CYMHS respond to those experiencing more complex and severe mental health problems. CAMHS/CYMHS also play a lead role in promoting quality mental health responses in other sectors.

http://www.health.vic.gov.au/mentalhealth/camhs/

## Sexuality

Sexuality is an integral part of human development and includes gender, sexual identity, reproduction and sexual orientation (Jones & Chivers, 2011). Whilst there is a limited literature on issues of sexuality of children with ASDs, there is no doubt that it is an important issue that should be considered throughout the lifespan. The broader literature on children and young people with developmental disabilities indicates that the information and support individuals with a disability have influences their sexual health, their ability to make informed decisions, develop relationships and remain safe. Furthermore, lack of support may lead to exploitation, vulnerability to abuse, poor health and contact with the criminal justice system (Jones & Chivers, 2011). Young people with an ASD usually have to learn about social skills and relationships without the opportunity of peer group discussion and support available to typically developing adolescents (Howlin, 2005). Furthermore, individuals with an ASD have been found to show more difficulties with the external changes of the body during puberty (Hellemans et al., 2010).

Jones and Chivers (2011) identified a number of elements to sexual education for young people with learning difficulties. Many of these are also pertinent to those with an ASD and include:

- information about the changing bodies and integrity of their body
- rules about social sexual behaviour
- a safe environment
- support in developing positive sexuality
- skills in developing and maintaining friendships
- opportunities to develop intimate relationships
- opportunities to take risks to enable independence
- access to health services
- advocacy (p 195).

➢ The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health provides a range of supports and services related to children, adolescents and adults with a developmental disability and sexuality including human relations educational materials.

http://www.cddh.monash.org/sexuality-disability.html

## Cultural awareness

Culture is “the shared way of life including attitudes, beliefs, norms and values of people” (Powie, 2012, p. 63). There are inevitable stressors for people who are adapting to a new country, culture, social system and language. Families from culturally and linguistically diverse (CALD) backgrounds may experience stressors due to settlement issues, trauma, pre-post immigration experiences, unemployment, limited social support and poverty (Baasiri & Carroll, 2011). There may be additional cultural complexities to the adjustment and wellbeing of individuals with a disability, including those with an ASD, and their families. Cultural differences in family members’ responses to disability have been reported to influence levels of stress and long-term outcomes (Echemendia & Westerveld, 2006). Cultural awareness and sensitivity is important in the fields of disability and mental health.

Baasir & Carroll (2011) stated that “Clinicians need to adjust the way they provide health and mental health services, using knowledge of the culturally mediated values, attitudes, and experiences that apply to a given case, and through effective communication skills, and a willingness to advocate on behalf of families” (p. 44).

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Clients may come from any non-English background and may come from any age, gender, or religion.

http://www.adec.org.au/advocacy.html

- Cultural Diversity Plan for Victoria’s Specialist Mental Health Services (DoH)

The Cultural Diversity Plan for Victoria’s Specialist Mental Health Services provides a framework for improving the accessibility and responsiveness of mental health services to Victoria’s CALD communities. The Cultural Diversity Guide identifies a range of strategies to improve cultural responsiveness and high quality service provision. It provides examples of good practice, as well as guidance on additional resources and supports to respond to diversity for programs and agencies.

http://www.health.vic.gov.au/diversity/cald.htm

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# SECTION FIVE

## Adolescence (The secondary school years)

# Identification & referral (Adolescence)

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## Developmental concerns in the adolescent years

Adolescence is the transitional period and process of physical and psychological development from child to adult. Adolescence brings physical changes, but also changes in a person's sense of identity, feelings and behaviour.  Adolescents may struggle with their sense of identity, worry about being 'normal', have concerns about their attractiveness to others, take things personally or be moody. Their interests are often strongly influenced by their peer group and they may increasingly test rules and limits (Kail & Cavanaugh, 2011).

There are usually added complexities for those adolescents with an ASD at this time of change. Young people with an ASD usually have to manage and respond to the changes in physical, social and personality development without the opportunity for peer group discussion and support. This is particularly pertinent for those young people with Asperger's disorder or HFA who may be worried about relationships, their sexual development or their independence from family.

As our understanding of ASD has increased over the past decades, so has the number of adolescents diagnosed .  This is particularly so for those young people with Asperger's disorder who have not had a history of delayed cognitive or language development. For these young people, the increasing demands and changes during adolescence become more complex and difficult for the young person with Asperger's disorder or HFA to navigate. These difficulties often lead to discussion between parents and secondary school teachers or health professionals about their concerns.

## Screening

Screening involves the use of specific tests or examinations to identify those people in a population who are likely to have a particular condition or disorder (Baird et al., 2001; Oberklaid at al., 2002). Screens are not diagnostic, but sort out those who are likely to have the condition from those who are likely not to. Screening instruments can provide valuable information about a young person's development and behaviour and can provide a structure to talk about the need for referral for further assessment. An autism screen may be used by a medical practitioner or allied health professional to help guide referral and support.

- The Developmental Behaviour Checklist (DBC)

The Developmental Behaviour Checklist (DBC-P) is a parent-completed, reliable and valid autism screening tool for at-risk populations (Einfeld & Tonge, 2002). The DBC Autism Screening Algorithm (DBC-ASA) is a twenty-nine item scale used for discriminating children and young people (aged 4-18) with autism (Brereton et al., 2002). There is also a teacher version of the DBC (DBC-T) which allows educators to provide valuable additional information about the young person in a school setting. The DBC-T does not have an autism screening algorithm. The DBC-P (parent) has been translated into other languages, including Arabic, Chinese, Croatian, Dutch, Finnish, French, German, Greek, Hindi, Italian, Japanese, Malay, Norwegian, Portuguese, Portuguese (Brazil), Spanish, Swedish, Turkish and Vietnamese.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

## Referral

There are a number of factors that commonly prompt a referral for assessment during the adolescent years. These include increasing difficulties with the social or academic demands of the secondary school environment, or a change in emotions and behaviour that are a concern to their parents and teachers. The young person may have been diagnosed with another condition when they were younger (e.g. ADHD) but their behavioural and emotional characteristics have changed as they have matured and the original diagnosis requires re-evaluation. At times, the young person themself may become increasingly interested in understanding why they feel ‘different’ and are seeking some answers.

In Victoria there are a number of referral pathways for adolescents. This makes it confusing for the young person, parents and professionals alike. Typically, discussion between the young person’s parents and teacher/s triggers an initial referral to a GP, the Student Support Services Officer, or to a private allied health professional such as a psychologist. Onward referral may then be made to a specialist such as a paediatrician or child psychiatrist. Alternatively, the young person may be referred to a tertiary level service such as the regional CAMHS/CYMHS.

### i) General Practitioner

School aged children and adolescents are often referred to the local GP when there is a concern about their behaviour and development. Referral to a GP should include relevant supporting documentation and an indication of specific concerns and desired outcome (e.g. referral to child psychiatrist).

GPs can conduct an initial medical assessment and may use a screening instrument where appropriate to guide further referral. Ongoing referral may be to a medical specialist such as a Paediatrician or Child Psychiatrist, to an allied health practitioner, or to an ASDs assessment service such as CAMHS/CYMHS. GPs can also complete the necessary documentation for access to Medicare rebates for allied health services, assessment services and support through Centrelink.

GPs have a critical role in the ongoing monitoring of health issues over the lifespan for individuals diagnosed with an ASD.

### ii) Student Support Services Officers (SSSOs)

Students who attend a local government school are often referred to the Student Support Services Officer (SSSO). The SSSO programme is funded by the DEECD to provide specialised support for young people with additional needs or at risk of disengagement and their families in government schools. The program also aims to strengthen the capacity of schools to engage all students in education. SSSOs include psychologists, guidance officers, speech pathologists, social workers, visiting teachers and other related professionals who may conduct an initial assessment and provide ongoing support for the student and school staff. Initial assessment from a SSSO may also later be used to contribute to a diagnosis.

http://www.education.vic.gov.au/healthwellbeing/support/ssso.htm

### iii) Allied Health Practitioners

Initial referral may also be made to an allied health practitioner such as a Speech Pathologist, Psychologist, Special Education Teacher or Occupational Therapist for assessment and/or intervention. These clinicians typically work within a local community health centre or through a private practice. Initial assessment from an allied health practitioner may also later be used to contribute to a diagnosis.

Professional organisations have online lists of registered therapists

- Australian Psychological Society

http://www.psychology.org.au/findapsychologist/

- Occupational Therapy Australia

http://www.otaus.com.au/findanot

- Speech Pathology Australia

http://www.speechpathologyaustralia.org.au/about-spa/find-a-speech-pathologist

Further referral

Following an initial consultation and assessment with a GP, allied health practitioner or the SSSO, an onward referral may be made to a specialist such as a child psychiatrist or paediatrician. Referral may also be made to another health practitioner such as an audiologist to gather further information. Alternatively, the onward referral may be to the regional CAMHS/CYMHS. See next section for further details.

- Amaze (Autism Victoria) has a directory of services available through the information line. Ph. 1300308699

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

- The Association for Children with a Disability (ACD) has a comprehensive booklet titled 'Through the Maze' which outlines services and resources in Victoria for parents and children 0-18 years (translations available in community languages.)

http://www.acd.org.au/information/ttmb.htm

## Assessment & Diagnosis (Adolescence)

### ASDs assessment guidelines

Because the aetiology of ASDs is largely unknown, diagnosis relies on diagnostic criteria being matched with behavioural description, observation of behaviour patterns and the young person's course of development. A comprehensive multi-disciplinary assessment should always include expert clinical judgment combined with a range of valid and reliable standardized instruments. Currently, the international classification standard for establishing a diagnosis of autism and other pervasive developmental disorders is outlined in both the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revised, of the American Psychiatric Association (DSM-IV-TR) (APA, 2000) and the International Classification of Diseases and Related Health Problems (ICD-10) (WHO 1992). In Victoria, the DSM-IV-TR (APA, 2000) is used.

ASDs are complex disorders and undertaking an ASD assessment requires a rigorous, comprehensive and systematic approach. Professionals involved in ASD assessments require training, experience and supervision. In Victoria, ASDs assessment guidelines have been developed by Autism Victoria (2009). The 'Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders' provide a definition of ASDs, outline assessment standards and guidelines, and list eligibility criteria for government funding services. The guidelines advocate a multi-disciplinary approach to assessment using DSM-IV-TR criteria.

- Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders'

http://www.amaze.org.au/uploads/2010/11/ASD-Diagnosis-Assessment-Guidelines-Victoria.pdf

Whilst Autism Victoria's (2009) diagnostic process guidelines provide standards, the process of assessment varies from one service or clinic to another and, as such, children, young people and their families have different experiences. International studies have shown that parents are sometimes dissatisfied with the assessment process, and also with how the diagnosis was communicated to them (Chamak, Bonniau, Oudaya & Ehrenberg, 2011; Goin-Kochel et al., 2006; Howlin & Moore, 1997). The time of diagnosis is a critical time when parents are told their child has a lifelong disability . It is an experience that parents don't forget. It is suggested that the manner in which professionals discuss the diagnosis with parents may affect the parents ability to cope and adapt, as well as their perception and subsequent care of their child (Silove, 2011).

Howlin and Moore (1997) surveyed 1,295 parents of children aged 2-49 years in the UK to investigate their views of the diagnostic process. Results indicated that parents were frustrated by lengthy delays, with parental satisfaction with the diagnostic process reported to be affected by the length of time they waited before receiving a final diagnosis. There was also an association between the nature of the diagnosis, with an unequivocal diagnosis of autism or Asperger's far more satisfactory than a vague descriptor of 'autistic traits'. Brogan and Knussen (2003) investigated the determinants of satisfaction of 126 parents of the disclosure of a diagnosis of an ASD. They reported that parents were more satisfied with the disclosure if they rated the manner of the professional and quality of information provided positively. In particular, parents were more satisfied when they had been given written information, an opportunity to ask questions and felt that their own concerns had been accepted by the professionals. The findings concurred with Howlin and Moore's (1997) previous study that parents were more satisfied when given a definite diagnosis. Brogan and Knussen (2003) also found that parents were more likely to be satisfied when given the diagnosis of Asperger's, rather than autism. Goin-Kochel, Mackintosh & Myers (2006) reported in their web-based study of nearly 500 parents in the US that parents were more satisfied with the diagnostic process when they saw fewer professionals and when their children received a diagnosis at a younger age. Higher levels of parental education and income were also associated with greater satisfaction.

In a more recent study in Ireland, Braiden, Bothwell & Duffy (2010) reported on several factors that parents reported as contributing to positive experience during the assessment process. These included;

- having their initial concerns listened to
- receiving the child's diagnosis in person
- receiving written information
- help in applying for this information.

Chamak et al. (2011) surveyed nearly 300 French parents to investigate their experience of the autism diagnostic process. In line with previous studies (DeGiacomo and Fombonne, 1998; Goin-Kochel et al., 2006; Howlin and Asgharian, 1999; Siklos and Kerns, 2007), they reported a delay between parents' initial worries, first consultation and diagnosis. Chamak et al. (2011) also reported on the mixed emotions encountered by parents including relief, sadness, anger, distress and dismay. In accordance with the literature in relation to children with developmental disabilities and life threatening illness (Wooley et al., 1989; Sloper & Turner, 1993), the researchers discussed the significance of the manner of the teller, and parents' perception that this had affected their ability to cope with their child's autism. In particular, they noted the importance of providing the diagnosis directly, with a large amount of information and support and concluded that when information was repeated, clarified, and explained in straightforward language, and when a list of support services were given parents felt more satisfied with the consultation. Other studies have reported that parents often comment on the lack of information available about service provisions, such as appropriate education options, social services, leisure activities, health services, financial entitlements and on how these services are accessed and organized (Osborne & Reed, 2008; Renty & Roeyers 2006).

Best practice guidelines on the education and training requirements on appropriate procedures to inform parents of their child's disability include those from the Informing Families Project (2007) in Ireland. The guiding principles are pertinent to discussing a diagnosis of ASD and include:

- Family centred disclosure
- Respect for child and family
- Sensitive and empathetic communication
- Appropriate, accurate information, positive, realistic messages of hope
- Team approach and planning
- Focused and supported implementation of best practice.

(National Federation of Voluntary Bodies, 2007).

Clearly it is important to remember that *how* the assessment process is conducted is just as important as *what* is provided.

Assessment and diagnosis of adolescents presents with particular challenges. It is sometimes difficult to obtain an accurate and detailed developmental history of adolescents as parent's memories of their child's milestones and behaviour fades over time. Adolescents with an ASD present differently depending on their current symptoms which change over time, their cognitive ability, and their life experiences.

Co-morbid conditions may 'over-shadow' the diagnosis of an ASD. As a consequence parents and professionals may attribute all of the young person's presenting behaviour to a condition such as anxiety or depression, rather than understanding a number of conditions exist together. That is, the young person may have an anxiety disorder *and* Aspergers' disorder. These comorbid conditions may be related (e.g. there is an increasing likelihood of the onset of other psychiatric conditions in individuals with an ASD in the adolescent years) or they may be independent of each other (e.g. the young person has leukaemia and an ASD).

There is also the complexity of an alternative or differential diagnosis. In the adolescent years, common differential diagnosis and/or co-morbid conditions include intellectual disability, depression and other mood disorders, anxiety disorders, schizophrenia and other psychotic disorders, communication disorders, schizotypal disorder, attention deficit disorders, behavioural disorders, and substance abuse. Thorough assessment by professionals with experience and expertise in ASDs and mental health problems is required understand differential diagnosis and comorbid conditions.

## Components of diagnostic assessment for adolescents usually includes:

**Comprehensive medical assessment, for example:**

Audiology, vision, test for genetic disorders

**Developmental and family history, for example:**

Autism Diagnostic Interview – Revised (ADI-R), a semi-structured interview with the young person's primary caregiver (Le Couteur et al., 2003).

**Observation of the young person's behaviour and interactions, for example:**

Autism Diagnostic Observation Schedule (ADOS-2) a semi-structure session with the young person (Lord et al., 2000)

**Interview with the young person**

**Developmental/cognitive assessment using a standardized test, for example:**

Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV), for children between the ages of 6 and 16 years (Wechsler, 2003).

Wechsler Adult Intelligence Scale (WAIS-IV), sixteen years and over (Wechsler, 2008)

**Adaptive functioning, for example:**

Vineland Adaptive Behavioural Scales (VABS-II) **(**Sparrow, Cicchetti, & Balla, 2005)

**Structured language assessment (expressive, receptive pragmatic language) , for example:**

Clinical Evaluation of Language Fundamentals - Fourth Edition (CELF-4 Australian), (Semel, Wiig & Secord, 2006)

**Assessment of emotions and behaviour/mental health examination, for example:**

Developmental Behaviour Checklist - Parent

Developmental Behaviour Checklist - Teacher version (Einfeld & Tonge, 2002)

**Other assessments to investigate sensory problems, motor planning and co-ordination**

**Comprehensive and sensitive feedback to the parents/caregivers and the young person**

## ASDs assessment services

### i) Private ASDs assessment

Medical and allied health practitioners (speech pathologist, psychologist, occupational therapists, special education teachers) working in private practice may have the relevant training, experience and expertise to conduct assessments that contribute to the formulation of a diagnosis. Professional ASD assessment standards are detailed in Autism Victoria Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of ASDs (Autism Victoria, 2009).

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

### ii) Child and Adolescent/Youth Mental Health Services (CAMHS/CYMHS)

Within each region in Victoria there is a specialized child and adolescent ASDs assessment service with a highly skilled multidisciplinary team that provides assessment, diagnosis and treatment planning of ASDs. Each team has a senior clinician to coordinate the ASDs assessment and diagnostic process, oversee the delivery of quality early intervention and ongoing clinical care within the mental health service, and facilitate referral pathways to other appropriate support services. In addition to coordinating service and demonstrating leadership within the mental health service system regarding ASDs, the regional coordinators link in with key service providers such as paediatricians, disability services, schools and student support services officers (SSSOs) to assist with local coordination of ASDs service delivery. The coordinators are supported by a dedicated state-wide ASDs coordinator located at Mindful: Centre for Training and Research in Developmental Health, University of Melbourne.

As a tertiary level service, the CAMHS/CYMHS typically see children with more complex, high risk or crisis level needs. CAMHS/CYMHS are not able to meet the demand of ASD assessments alone and work carefully with partners in the private and public sector to meet the shared obligation of assessment, education and treatment for children and families. CAMHS/CYMHS ASDs coordinators support community partners in their work where possible, and confer on or assess the most complex cases. They serve as an important hub of expertise in ASD assessment and treatment and further support clinicians in their region with professional development and secondary consultation.

## Regional CAMHS/CYMHS ASD coordinators

| | | | |
|---|---|---|---|
| North east | Kirsty Jungwirth | 9496 3620 | Kirsty.JUNGWIRTH@austin.org.au |
| | | | |
| Inner south | Mary Fleming | 8552 0555 | M.Fleming@alfred.org.au |
| | | | |
| South east Endeavour | David Moseley | 9594 1300 | david.moseley@southernhealth.org.au |
| | | | |
| Eastern | Sian Hughes | 9843 1200 | Sian.Hughes@easternhealth.org.au |
| | | | |
| North west | Frances Saunders<br>Fiona Zandt | 9345 6011 | Frances.Saunders@rch.org.au<br>Fiona Zandt@rch.org.au |
| | | | |
| Orygen | Beth Angus | 1800 888 320 | Beth.Angus@mh.org.au |
| | | | |
| Gippsland | Ruth Turnbull | 5128 0100 | rturnbull@lrh.com.au |
| | | | |
| Barwon | Fiona Walker | 5226 7075 | fionaw@barwonhealth.org.au |
| | | | |
| Glenelg (south west) | Mary-Anne Holley<br>Robert McGregor | 5561 9100 | mholley@swh.net.au<br>RMcGregor@swh.net.au |
| | | | |
| Grampians | Tina Cocking | 5320 3030 | Tinac@bhs.org.au |
| | | | |
| Campaspe & Southern Mallee | Julie Gillin | 5440 6500 | JGillin@bendigohealth.org.au |
| | | | |
| North-east Hume | Susan McLees<br>Jo Freudenstein<br>Megan Hollingworth | 02 6024 7711 | Susan.McLees@wrhs.org.au<br>joanna.freudenstein@awh.org.au<br>megan.hollingworth@awh.org.au |
| | | | |
| Goulburn & Southern | Susan Galambos | 5832 2160 | susan.galambos@gvhealth.org.au |
| | | | |
| Northern Mallee | Mirabel McConchie | 5022 3500 | mcconchiem@ramsayhealth.com.au |

- Child and Adolescent Mental Health Services (CAMHS/CYMHS)

http://www.health.vic.gov.au/mentalhealth/camhs/

- Mindful: Centre for Training and Research in Developmental Health

A training program in assessment, diagnosis and treatment for Paediatric fellows, Psychiatric registrars and mental health clinicians has been funded by the DoH and designed and delivered by Mindful: Centre for Training and Research in Developmental Health, University of Melbourne. Regular training is provided on the fundamental of ASDs assessment and diagnosis and is enhanced by follow-up seminars on assessment and treatment for adolescents and young adults, and workshops on specific assessment instruments (e.g. ADOS).

http://www.mindful.org.au/Home.aspx

Ongoing multi-disciplinary assessment should form the basis for individual program planning. This allows parents, professionals and the young person where appropriate, to work together to better understand ASD symptoms, cognitive profile, psychopathology, adaptive skills and strengths and weaknesses.

## Intervention & education (Adolescence)

As the aetiology of ASDs has not yet been determined in the majority of cases, there is no specific treatment for these complex neuro-developmental conditions. Conflicting opinions over treatment methods continue while researchers attempt to identify what kinds of interventions are most efficacious, the degree of improvements that can be expected and if an intervention focussing on one aspect of autism results in concurrent improvements in other areas. While there has been a focus on interventions and treatments for very young children with an ASD over the past several decades, there is a dearth of research on treatments for adolescents and adults with an ASD. Francis (2005) stated that, as there is "…no cure at present, the word "treatment" should only be used in a very limited sense, reflecting interventions aimed at helping people with ASD to adjust more effectively to their environment" (p. 493).

### Helpful questions for parents

Will the treatment result in harm to my child? (physical or psychological harm)

Is the treatment developmentally appropriate for my child?

How will failure of the treatment affect my child and family?

Has the treatment been validated scientifically?

How will the treatment be integrated in to my child's current program? Freeman (1997)

## Best practice guidelines

Papers on evidence based treatments and interventions provide important information for parents and professionals to assist them in making informed decisions about educational interventions.

Iovannone, Dunlap, Huber & Kinkaid (2003) were interested in determining if the core elements of effective educational programs identified in reports on young children with an ASD were consistent with practices for older children and adolescents. In their paper on effective educational placements for students with an ASD they listed six core elements of educational practice with empirical support.

The core elements included:

- the provision of individualised supports and services for students and families
- systematic instruction, comprehensive and structured learning environments
- specialised curriculum content
- a functional approach to difficult behaviours
- family involvement

### The National Standards Reports

More recently, a report from the National Autism Centre (2009) in the USA provided information about the level of scientific evidence that existed in support of educational and behavioural treatments for individuals (0-22 years) with an ASD in the National Standards Report. The report used four levels of strength of evidence (established, emerging, unestablished and ineffective) and was the first to have also provided information about treatment effectiveness based on age, diagnostic group and treatment targets. The National Autism Centre's Standards Report (2009) recommended that parent-professional teams give serious consideration to 'established' treatments, do not begin with 'emerging' treatments, and only consider 'unestablished' treatments after additional research has been conducted and shown favourable outcomes. Further details of each of the interventions can be obtained by reading the report.

Seven ‘established’ treatments were identified for adolescents between the ages of 10-14 years. These included:

- Antecedent package
- Behavioural package
- Modelling, peer training
- Schedules
- Self-management
- Story-based interventions

Only four treatments were identified as ‘established’ for adolescents between the ages of 15-18 years. These included:

- Antecedent package
- Behavioural package
- Modelling
- Self-management

The National Standards Report also identified many ‘emerging’ treatments for adolescents and stated that:

> “Given the limited research support for Emerging Treatments, we generally do not recommend *beginning* with these treatments. However, Emerging Treatments should be considered promising and warrant serious consideration if established treatments are deemed inappropriate by the decision-making team” (p. 76).

Nine ‘emerging’ treatments were identified for children between the ages of 10-18 years which included:

- cognitive behavioural intervention package
- exercise
- imitation based interventions
- initiation training
- scripting
- social skills package
- structured teaching
- technology-based treatment
- theory of mind training

It is of equal importance for us to be informed about those treatments that are identified as ‘unestablished’. Unestablished treatments are described as those for which there is little or no evidence in the scientific literature to draw firm conclusions about the effectiveness of these interventions with individuals with ASD. The NAC guidelines state that “There is no reason to assume these treatments are effective. Further, there is no way to rule out the possibility these treatments are ineffective or harmful” (p. 70). This is because the quality, quantity, and consistency of research findings have generally been poor or do not apply to individuals with ASD.

The following treatments have been identified as having an ‘*unestablished’* level of evidence:

- Academic Interventions
- Auditory Integration Training
- Facilitated Communication
- Gluten- and Casein-Free Diet
- Sensory Integrative Package

Furthermore, the NAC guidelines state that:

> “There are likely many more treatments that fall into this category. That is, there are many treatments for which no research has been conducted or, if studies have been published, the accepted process for publishing scientific work was not followed. There are a growing number of treatments that have not yet been investigated scientifically. These would all be Unestablished Treatments. Further, any treatments for which studies were published exclusively in non-peer-reviewed journals would be Unestablished” (p.70).

- National Standards Report (2009)

http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf

More recently, the NAC published two further reports.

- ‘Evidence-based practice and autism in the schools: A guide to providing appropriate interventions to students with ASDs’ (2011). This manual is a guide for teachers that provides an outline of ASDs, summarises research findings describes the importance of professional judgment, and the values and preferences of families in evidence based practice.

- ‘Evidence-based practice and autism; providing information and resources for families of children with ASDs’ (2011). This manual begins with a review of the ASDs and describes effective treatments. Other topics include the importance of professional judgment, the role of family preferences and values in the decision-making process, and factors to consider when choosing a team of professionals. The manual was co-authored by professionals and parents of children with an ASD.

http://www.nationalautismcenter.org/index.php

## Secondary school options

There are a range of schooling options for children in the secondary school years which provides parents and students with important, and sometimes difficult, decisions. Advice from professionals, family and friends can sometimes be conflicting or inaccurate.

### i) State government schools (DEECD)

State government schools include the primary and secondary schools, autism specific schools, specialist schools and special developmental schools (SDS). Some government schools have a 'base room' or specialised classroom within the school to cater for students with ASD.

Three levels of support are provided for students with an ASD by DEECD including:

a) A whole school approach to building a positive school culture

A range of resources may be provided via the Student Resource Package, through specific early identification and intervention programs, or through student support services. The student support services officer (SSSO) program provides specialised support to children and young people with additional needs or at risk of disengagement and their families, and to strengthen the capacity of schools to engage all students in education. SSSOs include psychologists, guidance officers, speech pathologists, social workers, visiting teachers and other related professionals.

http://www.education.vic.gov.au/healthwellbeing/support/ssso.html

b) A targeted approach to identify and address need

This may include establishing a Student Support Group (SSG) and an Individual Learning Plan (ILP) developed for each student. A Student Support Group is a partnership involving parents, school representatives and professionals to develop coordinated support for the student through the development of specific educational goals strategies.

c) An intensive response to address need.

The Program for Students with Disabilities (PSD) is an intensive program for eligible students. The Program supports the education of students with disabilities in Victorian government schools by providing schools with additional resources. The PSD is available for eligible students in the categories of physical disability, visual impairment, severe behaviour disorder, hearing impairment, intellectual disability, ASDs and severe language disorder with critical educational needs.

http://www.education.vic.gov.au/healthwellbeing/wellbeing/disability/handbook/default.htm

- More Support for Students with Disabilities National Partnership

In 2012, the Commonwealth and Victorian governments developed a range of strategies under the ‘More Support for Students with Disabilities National Partnership’ to ensure better support for students with a disability. The partnership initiatives target four key areas: building school capacity, strengthening options, utilizing technology and a focus on teaching and learning (DEECD, 2012). Strategies include:

  - Autism teacher coaches and school support in each region
  - Autism inclusion support coordinators (ISPs)
  - Autism teacher specialisation scholarships
  - Expert consultation for ASD through Autism Victoria (amaze)
  - Inclusion Online professionals learning portal
  - Disability standards for education – professional learning for schools

http://www.education.vic.gov.au/healthwellbeing/wellbeing/mssd.htm

### ii) Independent schools

There are many independent schools throughout Victoria including specialist schools for students with learning difficulties (e.g. SDS) and for students with an ASD (e.g. Mansfield Autism Statewide Services). Other independent schools offer educational programs based on the approaches of Montessori or Steiner, whilst others are denominational. Independent schools Victoria provides a handbook outlining support for students with a disability which includes Disability standards for education and guidelines for Program Support Groups (PSG).

Australian Government targeted funding for eligible students with disabilities (including ASDs) in independent schools is available through the ‘Literacy, Numeracy and Special Learning Needs Program’. Victorian Government targeted funding for eligible students are available through the ‘State Support Services Program’. The criteria for eligibility of funding for students with an ASD attending an independent school are similar to that used in government schools; however the amount of funding allocated may be less.

- Association of Independent Schools, Victoria http://www.independentschools.vic.edu.au/

### iii) Catholic Schools

The Catholic Education Office provides assessment services and student learning program support, as well as assistance for schools in devising and implementing Individual Learning Plans (ILP) for students with additional learning needs, including those with an ASD. The criteria for eligibility of funding for students with an ASD attending a catholic school are similar to that used in government schools; however the amount of funding allocated may be less. The Australian Catholic University also provides services including counselling and educational assessments through the Melbourne Psychology and Counselling Clinic .

- Catholic Education Office http://www.ceo.melb.catholic.edu.au/

### iv) Home schooling

Home schooling is a recognised alternative to attending government or registered non-government schools. That involves parent/s taking responsibility for the planning, implementation and assessment of their child’s education. Parents interested in home schooling must register with the Victorian Registration and Qualifications Authority (VRQA), a statutory authority responsible for the registration and accreditation of education and training providers. The *Education and Training Reform Act* 2006 requires that all children of compulsory school age (6 to 17 years) are enrolled in a school, or registered for home schooling.

- Home schooling in Victoria: A guide to services and support (DEECD, 2010)

http://www.eduweb.vic.gov.au/edulibrary/public/commrel/aboutschool/homeschoolingbooklet.pdf

## Transition to secondary school

As yet there is no literature on evidence-based management of transition to secondary school for students with an ASD. This major educational transition places greater demands on the student both academically and socially. The stressors of moving to a new place, having a larger and more complex peer group, meeting new teachers, and increased responsibilities can contribute to students feeling unsettled or overwhelmed. It can be an exciting step, but may also be a source of stress and anxiety for parents, professionals and the young person (Brereton & Bull, 2012). This may also be the case for those students with an ASD making the transition from one year level to the next, and from secondary school to post school options. Adolescents with autism usually do not do as well as their typically developing peers academically and the social gap widens during the adolescent years (Arick, Krug, Fullerton, Loos & Falco, 2005). Leisure pursuits are more likely to be solitary rather than community based (Jennes-Coussens, Magill-Evans & Koning, 2006) and the young person is vulnerable to mental health difficulties, particularly if there has been insufficient preparation for change (Tonge et al., 2008). Successful transition requires careful planning, preparation and communication that lead to a shared understanding of each student.

Difficulties may arise for young people with an ASD during times of transition because of:

- the student's ASD symptoms (social, communication, behaviour)
- the student thinking and learning style
- difficulties in managing change
- particular difficulties in managing stressful situations
- difficulties in both understanding and using language
- co morbid conditions (health, ID and mental health problems) (Brereton & Bull, 2012).

The National Autistic Society (2002) published 'Good practice guidelines for services – adults with Asperger's syndrome'. The guidelines suggest the management of transition for individuals with Asperger's disorder, but could also be applied to all students with an ASD moving between primary and secondary school.

Recommendations include assessing the student’s:

- Health needs
- Education needs
- Emotional and behavioural development needs
- Identity needs
- Family and social relationships needs
- Social presentation
- Self care skills needs

The NAS guidelines (2002) also recommend to:

- Form a transition planning group
- Map out links between schools and agree on a support pathway for transition
- Provide the student and family with consistent support and information
- Name a person to oversee the transition

In Victoria, there are a number of supports and training opportunities to encourage planned approaches to transitions.

- ‘ASDs: Planning a successful transition to secondary school’ (Brereton & Bull, 2012)

The ‘ASDs: Planning a successful transition to secondary school’ program has been developed to support parents and professionals working in primary schools, specialist schools and secondary schools, and ensure a positive experience of transition. Like the transition to primary school program, the program is not intended to be a "crash course" in ASDs. Instead, the focus of the program is on creating an effective transition team and working together to develop a transition plan. The ½ day workshop for the transition team provides an overview of basic information about the core features of ASDs and how they affect young people’s thinking and learning, communication, social relating skills, emotions, behaviour, and mental health particularly in times of change and growth, including during adolescence. The program equips staff and families with relevant and useful resources to assist in the transition planning. Factsheets and ‘ASDs transition learning and development statements’ are also available.

http://www.education.vic.gov.au/about/programs/needs/Pages/autism.aspx

- Transition to Secondary School: Supporting students with a disability in the transition to Victorian government secondary schools (ACD)

Transition to Secondary School provides information on all aspects of school transition from choosing a secondary school and planning for the right supports to be in place, to developing positive partnerships and raising concerns.

Family stories and specific topics covered in the resource include: Transition Planning Guide; Secondary school options; Program for Students with Disabilities Year 6-7 Review; Choosing a secondary school; Enrolment procedure; Transition planning with the Student Support Group; Supports for students with a disability at government secondary schools; Making the transition; Developing a positive partnership with the school; Raising a concern; Advocating for your child; Towards independence; Advocacy organisations; and Web resources.

http://www.acd.org.au/information/transitionb.htm

## University and Technical & Further Education (TAFE)

Studying at University and TAFE can be an exciting and appropriate option for some young people with an ASD, following secondary schooling. However, there are particular challenges due to the discontinuities between secondary and tertiary education. These include:

- larger number of students
- larger campus
- non compulsory attendance
- lecture and tutorial structure
- less interaction with lecturers
- complexity of timetable and organisational requirements
- lack of structured 9.00-3.30 daily routine
- expectation of independence
- self-directed learning
- distance from home

In 2002, the National Autistic Society prepared guidelines related to the transition to university for students with Asperger's disorder (NAS, pp. 54-55) that are pertinent to the Victorian context for individuals with an ASD. These included the following:

- The student should have the support in order to make the move into college or university
- Students will often require advice about applying for support and asking the right questions before choosing a course
- Form a transition planning group
- Awareness sessions on Asperger's Disorder to be taken up by college/university, for all staff – A 'Systems approach' (reception, tutors, student counsellors...)
- Learning support, counsellors and disability officers will benefit from 'job specific' training on Asperger's Disorder to enable them to provide effective pastoral support.
- A coherent protocol for students entry into college/university including:
    - ✓ enrolment forms with mention of developmental difficulties such as Asperger's
    - ✓ stress reducing 'welcomes' (e.g. prior contact with an personal tutor, home visit)
    - ✓ ensuring funding is in place for any learning support before term starts
    - ✓ good induction and orientation (e.g. maps of the campus and important contacts)
    - ✓ a flexible approach (e.g. allowing visits during holidays for familiarisation)

- ✓ establishing positive contact with parents, when appropriate.
- ✓ colleges locally should discuss good practice and share ideas about how best to support students.
- ✓ colleges should consider Asperger's Disorder specific courses, 'open-learning' or outreach courses to assist those who find traditional provision prevents them from learning.
- ✓ colleges should consider courses which help prepare people for work, by developing closer links with employers, and which address the specific employment needs of people with Asperger's Disorder

- ➢ Supporting tertiary students with ASD in University and TAFE (LaTrobe Uni)

LaTrobe University has a useful website with information for university and TAFE students diagnosed with an ASD, their parents, and tertiary staff. The website includes information on issues such as what to expect, disclosure of ASD diagnosis, further resources, information on The Disability Standards for Education (2005) and the the Disability Discrimination Act (1992)**.**

http://www.latrobe.edu.au/otarc/info/support/students/transition-and-orientation

- ➢ Futures for Young Adults

Futures for Young Adults (FFYA) is a Victorian government program that provides information, advice and support for up to three years to young people with a disability to help them make a successful transition from school to further education and employment. The type of support provided includes advice and guidance regarding the availability of post school options and referral to appropriate post school programmes, and the provision of funding to specialist disability services. FFYA can provide funded support for disability specific services for young people for whom generic community services are not able to meet their needs.

http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/futures-for-young-adults-2011-school-leavers-information-sheet

- Exploring the Possibilities: Post School Options for Young People with a Disability

A useful guide produced by DHS, in conjunction with DEECD and the Department of Innovation, Industry and Regional Development and the Victorian Advocacy League for Individuals with Disability Inc. (VALID).

http://www.dhs.vic.gov.au/__data/assets/pdf_file/0006/594645/exploring-possibilities-young-people-disability-2009-v1.pdf

- Disability Liaison Units

Disability Liaison Officers (DLOs) are employed at each TAFE Institute in Victoria and University and may be able to provide the following:

- support for assessment requirements (additional time, scribe, reader)
- academic Support Workers (note takers, interpreters, readers)
- access to adaptive technology (voice activated software)
- alternative format course materials (Braille, disk)
- liaison with lecturers / teachers; physical access to facilities
- referral to other support services (counselling, health, housing, financial aid)
- enrolment and campus orientation

Work Education Units and Disability Liaison Units within TAFE Institutes operate under different structures and funding arrangements.

- Preparing for Higher Education: A Victorian guide for students with a disability

A booklet funded by the Australian Government under the National Disability Coordination Officer Program (2012).

http://ndco.wodongatafe.edu.au/Data/Sites/1/1710_ndco_preparingforuniversitybooklet_190912_web.pdf

- Preparing for TAFE: A guide for Students with a Disability in Victoria (2010).

A booklet funded by the Australian Government under the National Disability Coordination Officer Program

http://ndco.wodongatafe.edu.au/Data/Sites/1/0699_ndco_disabilityguidebook_191109web.pdf

- Special Entry Access Scheme (SEAS)

The Special Entry Access Scheme (SEAS) through the Victorian Tertiary Admissions Centre (VTAC) for applicants who have experienced educational disadvantage. SEAS does not change a students educational results or qualifications. It enables course selection officers to recognise that results or educational progress may have been affected by circumstances in the SEAS application, and to consider the effect of those disadvantages. Having a SEAS application does not guarantee an offer at a tertiary institution. Category 5 is for applicants who have experienced educational disadvantage as a result of a disability or medical condition.

http://www.vtac.edu.au/who/seas.html

## Apprenticeship or traineeships

An apprenticeship or traineeship is a training contract between an employer and an employee in which the apprentice or trainee learns the skills needed for an occupation or trade. An apprenticeship or traineeship can be full-time or part-time basis and can be used as a valuable stepping stone to start a career in an industry for anyone of working age.

An apprentice or trainee can learn valuable, nationally recognised job skills, get paid while learning and combine formal training from a TAFE or training provider with workplace-based training

Students who are still at secondary school who want to complete VCE or VCA can complete a school-based apprenticeship or traineeship where time is spent at school, with the employer, and and also doing training with a TAFE or training provider.

| | |
|---|---|
| ➢ Apprenticeship Field Officers | ph. 1300 722 603 |

Apprenticeship Field Officers support apprentices, trainees and employers. Apprenticeship Field Officers are responsible for giving regulatory advice and support to apprentices and trainees and their employers, including:

- investigating disputes between apprentices or trainees and employers
- supporting apprentices or trainees who are victims of workplace violence and harassment
- counselling and offering advice to apprentices, trainees and employers on training and other matters.

Apprenticeship Field Officers are also authorised officers with certain powers available to them under the *Education and Training Reform Act 2006* to help make sure that employer, apprentice and trainee obligations under a training contract are being met.

http://www.education.vic.gov.au/training/learners/apprentices/Pages/default.aspx

- Apprenticeship Support Officers ph. 1300 722 603

Apprenticeship Support Officers give support and guidance to all apprentices, aged 15 to 24, in the first year of their apprenticeship. Apprenticeship Support Officers offer advice and assistance on personal and workplace issues and work with Registered Training Organisations, Australian Apprenticeship Centres and other service providers to deliver an integrated apprenticeship support service. The Apprenticeship Support Officer Program aims to increase the rates of apprenticeship completion by providing targeted support to apprentices in the early stages of their apprenticeship.

http://www.education.vic.gov.au/training/learners/apprentices/Pages/default.aspx

- A Guide to Apprenticeships and Traineeships: Apprenticeships and traineeships in Victoria (DEECD, 2011)

http://www.education.vic.gov.au/Documents/training/learners/apprentices/guideapprtrain.pdf

## Employment

The transition from school or tertiary education to employment presents challenges for most young adults, however the challenges are likely to be more significant and particularly stressful for individuals with an ASD. There is evidence that many adults with an ASD remain without paid full-time employment (Howlin, 2003). Yet people with an ASD may thrive in a supportive, structured and well-organised workplace environment and have a range of strengths such as an eye for detail, reliability and application of routine tasks that are advantageous to an employer. However, the individuals' ongoing difficulties with impaired communication, social interaction and restricted and repetitive behaviours can be the cause of ongoing difficulties. Difficulties with understanding social rules, resistance to change, problems working independently, the development of inappropriate work patterns and personal self-care can all create employment difficulties. Adults with an ASD may also be vulnerable to bullying or mistreatment in the workplace. Having an ASD, particularly adults with HFA and Asperger's, can lead to misunderstandings in the workplace by those unaware of their colleague's diagnosis.

The problems encountered in finding and keeping a job often arise from the lack of available information, advice and practical support that is ASD specific. Mawhood and Howlin (1999) also commented that the investment in educating young people successfully to the end of secondary school and beyond is lost when the skills that young adults acquire are not able to be transferred to the workplace. Some researchers suggest that even for those generally regarded as most capable, that many individuals live lives of isolation and dependence, with few opportunities to improve their quality of life (Mawhood and Howlin, 1999, Gerhardt, 2007).

Gerhardt, (2007) states:

> "This outcome, however, should be seen more as system failure and evidence of the fact that there is a "disconnect" between what research indicates is possible for adult learners with ASDs and the outcomes most commonly realized. As such, there is critical need to revisit the ways in which such learners are prepared for adult life beyond the classroom, in the community, and on the job" (p. 26).

Howlin (2003) provides some valuable strategies on supporting adults with an ASD in employment including making the job requirements explicit, providing adequate supervision and management structure, providing clear feedback, making the ‘rules’ of behaviour explicit, managing obsessions and resistance to change, and providing personal support. Howlin also highlights the importance of ongoing involvement from a multidisciplinary team of professionals such as a psychologist, social worker or psychiatrist who know the individual well, to support their employment opportunities and assist in avoiding problems from arising.

- Futures for Young Adults

Futures for Young Adults (FFYA) is a Victorian government program that provides information, advice and support for up to three years to young people with a disability, to help them make a successful transition from school to further education and employment. The type of support provided may include advice and guidance regarding the availability of post school options and referral to appropriate post school programs and the provision of funding to specialist disability services. FFYA can provide funded support for disability specific services for young people for whom generic community services are not able to meet their needs.

http://www.education.vic.gov.au/aboutschool/careers/community.htm#1

- Youth Employment Scheme (YES)

The Youth Employment Scheme (YES) scheme provides traineeship opportunities within the Victorian Government for young people aged between 15 and 24. The aims of the scheme is to increase the participation of people in their communities and in the workforce, assist young people to gain paid work experience, training and qualifications that lead to sustainable employment and assist communities to meet future skill and employment needs

Applicants must be aged between 15 and 24 (as at the start of the traineeship), currently unemployed or not working more than 15 hours per week, not currently engaged in tertiary education, available for work and without a university qualification.

http://www.dbi.vic.gov.au/employment-with-us/employment-programs/youth-employment-scheme

- Disability Employment Services

The Disability Employment Services (DES )are a national network of community and private organisations dedicated to helping people with disability find work and keep a job in the open labour market. Under Disability Employment Services, all eligible job seekers with disability, injury or health condition are able to receive assistance from an employment service provider to prepare for, find and keep a job. Disability Employment Services include two programs, the Disability Management Service and the Employment Support Service.

The Disability Management Service provides assistance to people with disability, injury or health condition who need the assistance of Disability Employment Services and who might need irregular or occasional support to keep a job.

The Employment Support Service provides assistance to people with permanent disability and who require regular, ongoing support to keep a job.

http://jobaccess.gov.au/Services/A-Z_list/Pages/DisabilityEmploymentServices.aspx

- Alpha Autism

Alpha Autism specialises in the provisions of day service programs which are client focused and based on evaluated techniques aimed at assisting adults with an ASD in their transition from school to independence, employment opportunities and social inclusion. Alpha's employment services address the needs of employers and clients, ensuring successful matches are made for sustained employment outcomes and community lifestyles.

Funding for many of Alpha Autism's services is provided by the Department of Human Services (Victoria) Individual Support Packages and through Department of Workplace Training for the provision of Employment Services. In addition to this, clients and their families/carers can access fee-for-service support as needed.

http://www.alpha-autism.org.au/

- Making the transition to an apprenticeship or traineeship (2012)

A booklet funded by the Australian Government under the National Disability Coordination Officer Program. Easing the Transition into an Apprenticeship or Traineeship for people with a disability.

http://www.ndcoceagroup.com.au/uploads/NDCO-Files/TransitionResources/NDCO%20Transition%20to%20Apprenticeship%20-%20June%202012.doc

- Disability Employment Services

Disability Employment Services (DES) were formerly known as Disability Employment Networks and provide eligible jobseekers with disability, injury or health condition, access to individually tailored employment services suited to their needs.

http://jobaccess.gov.au/Services/A-Z_list/Pages/DisabilityEmploymentServices.aspx

To find the nearest DES provider:
http://jobsearch.gov.au/provider/ProviderLocation.aspx?maplevel=2&ProviderType=DES&regionkey=VIC

## Community participation and recreation

There are many opportunities for participation in community activities for individuals with an ASD. There are universal activities such as fitness clubs, pools, sporting groups, libraries, exhibitions and social clubs that are available for all Victorians. There are also a wide range of specific groups and activities for adults with a disability, or for those with an ASD.

Physical exercise and leisure activities for individuals with an ASD are attracting a growing body of research interest. The National Standards Report (2009) cited four peer-reviewed studies on the use of physical exercise for individuals with an ASD as a means of reducing problem behaviours or increasing appropriate behaviour, and rated physical exercise programmes as an emerging treatment. More recently, Lang et al. (2010) conducted a systematic review of physical exercise interventions for individuals with ASDs and reported a decrease in stereotypy, aggression, and off-task behaviour, and an increase in on-task behaviour in response to physical activities such as jogging, weight training, swimming and bike riding. Improved physical and mental health and a positive effect on level of stress and quality of life in response to physical exercise have also been reported (Garcia-Villamisar & Dattilo, 2010; Garcia-Villamisar & Dattilo, 2011; Lang et al., 2010). Furthermore, Lang et al. (2010) suggested that deficits in motor abilities found in individuals with an ASD may be exacerbated by reduced opportunities to engage in physical activity Leisure pursuits for individuals with an ASD are found to be more likely solitary rather than community based (Jennes-Coussens, Magill-Evans & Koning, 2006)

- Access for all Abilities

Access for All Abilities is a Victorian Government initiative coordinated by Sport and Recreation Victoria. The program supports and develops inclusive sport and recreation opportunities for people with a disability throughout Victoria. Access for All Abilities providers work at a community level to develop inclusive sport and recreation opportunities for people of all abilities. Access for All Abilities providers work in all Victorian local council areas.

http://www.dpcd.vic.gov.au/sport/inclusive-sport/Access-For-All-Abilities

- Alpha Outbound

Alpha Outbound provides its members with an opportunity to participate in  social activities assisted by experienced support workers. This allows families and carers to access respite services.

http://www.alphaautism.org.au/respite-and-recreation/

- Alpha social club

Alpha Autism supports a Social Club and Girls Group specifically for adults living with an ASD. The clubs are organised by a committee of members who plan events for a six month period. Alpha assists in the co-ordination and planning of the social calendar but does not provide any staff or facilitators for the actual events. Events include exhibitions, shopping, eating out, sports and road trips. Members pay their own costs and need to arrange their own transport

http://www.alphaautism.org.au/social-club

- Asperger Syndrome Support Network (ASSN)

Asperger Syndrome Support Network (Vic) Inc. is a volunteer group of parents, carers, partners, professionals and individuals with Asperger's, who aim to provide support and information. One of their initiatives is a  monthly meeting and social events for adults with Asperger Syndrome.

http://www.assnvic.org.au/

- Asperger Syndrome Support Network (ASSN)

Asperger Syndrome Support Network (Vic) Inc. Has a useful website that contains information on leisure and social skills groups throughout Melbourne.

## Family information, education & support

Some parents report that they felt a decrease in the level of support and services they had received as their child moved from primary school to secondary school. Parents who had previously enjoyed regular contact with the 6th grade teacher miss that continuity of care during their child's secondary school years. Successful educational programs provide support for parents, as well as the child with an ASD, during the transition from one service to another with the knowledge that some families experience additional stress at this time.

A common recommendation from all of the ASDs best practice guidelines is that family involvement, support and education is critical (Dawson & Osterling, 1997; Francis, 2005; Howlin, 1998; Jordan et al., 1998; Kanthor et al., 1999; Le Couteur, 2003; National Research Council, 2001; National Autism Centre, 2009; Osbourn & Scott, 2004; Perry & Condillac, 2003; Rogers & Vismara, 2008; Simpson, 2005). In addition, a key component of family centred practice includes sharing information so that parents can make informed decisions (Dempsey & Keen, 2008; Dunst, 2002; Espe-Sherwindt, 2008; Gabovitch & Curtin, 2009; Shelton & Stepanek, 1994). Parent education programs can lead to positive child and parent outcomes (Schultz, Schmidt & Stitchter, 2011). There is empirical evidence that ASDs specific parent education and training programs contribute to the management of behavioural problems (Sofronoff & Farbotko, 2002; Whittingham, Sofronoff, Sheffield & Sanders, 2009) and improvement in functional communication in children with an ASD (Koegel, Symon & Koegel, 2002; McConachie, Randle, Hammal & LeCouteur, 2005; Moes and Frea, 2002). Studies have also reported positive effects of education programs in parents of children with an ASD on parental mental health and adjustment and self-efficacy (Bristol & Schopler, 1983; Bristol, 1984; Sofronoff & Farbotko, 2002; Tonge et al., 2006).

- Amaze (Autism Victoria)directory of autism services ph. 1300308699

Amaze (Autism Victoria)has a directory of services available through the information line.

http://www.amaze.org.au/discover/how-we-can-help-you/directory-of-services/

- Positive Partnerships

The ‘Positive Partnerships’ project is coordinated by Australian Autism Education and Training Consortium (AAETC). ‘Positive Partnerships’ provides workshops and information sessions for parents and carers of school aged children with an ASD and incorporates an Online Learning Portal where parents can access learning modules, resources, fact sheets, workshop content and support material.

http://www.autismtraining.com.au

- Autism Spectrum Australia (Aspect)

Autism Spectrum Australia (Aspect) provides a Positive Behaviour Support Program for children and young people (aged 6-25 years) with an ASD. The programme offers three levels of support.

1. Parents can access free Positive Behaviour workshops designed to support and assist families, carers and others to develop a greater understanding of the individual with ASD and the impact that this has upon learning, behaviour and development, and to design and implement an individualised positive behaviour support plan based upon an identified behaviour of concern.
2. Families of clients who require support at a more intensive level can participate in these Positive Behaviour Workshops, but, in addition, will be able to apply to receive individualised support to define specific goals and to design and implement a detailed behaviour support plan in the home and in other settings (including schools). Additional training and support will be provided to local services.
3. The highest intensity of support is longer term and designed to address issues with people who have more complex needs and enduring challenges. Clients requiring this level of support may be at significant risk of family breakdown or loss of school placement.

http://www.autismspectrum.org.au

- Family counsellors ph. 1300308699

Amaze (Autism Victoria)provides telephone or face to face autism specific family counselling.

Email: counsellor@amaze.org.au

- Through the Maze'  directory of disability services

The Association for Children with a Disability (ACD) has a comprehensive booklet titled 'Through the Maze' which outlines services and resources in Victoria for parent and children 0-18 years (translations available in community languages). Regional quick guides are also available.

http://www.acd.org.au/information/keycontactb.htm

- Parent Support Workers (ACD) ph. 1800654013

Available through the association for children with a Disability, parent support workers provide support by listening, understanding (they are themselves parents of children with a disability) and providing information and advice.

http://www.acd.org.au/support/indexb.htm

- Amaze (Autism Victoria)Information sheets

Amaze has some very helpful tip sheets on issues such as puberty, bullying and disability supports.

http://www.amaze.org.au/discover/about-autism-spectrum-disorders/changing-to-high-school-the-high-school-years/

- Support groups

ASDs specific Parent-to-parent support groups are held throughout metropolitan Melbourne and in rural centres. Groups specifically for fathers, siblings, grandparents and cultural groups are also available. Amaze (Autism Victoria)has a comprehensive list of these groups.

http://www.amaze.org.au/uploads/2011/08/Victorian-Parent-Support-Groups-Sep-20111.pdf

- Translating and Interpreting Services (TIS) ph. 131450

The Commonwealth Department of Immigration and Citizenship (DIAC) provide a Translating and Interpreting Services (TIS). TIS National provides a 24-hour, 7-days a week service for individuals and organisation (costs associated). It provides immediate telephone interpreting services, as well as pre-booked telephone and on-site interpreting.

http://www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Throughout Victoria. Clients may come from any non-English background and may come from any age, gender, or religion. The role of the Advoacy Program is to work in partnership with our clients to achieve goals that meet their individual needs and to ensure equity of access and participation in the community

http://www.adec.org.au/advocacy.html

- The Australian Advisory Board on Autism Spectrum Disorders

The Australian Advisory Board on ASDs is the national peak body representing people who have an ASD, their families, carers and helpers. The focus of the Advisory Board is working with governments to develop appropriate policies, disseminating information about ASDs and working with the Australian ASD community to build skills.

http://www.autismadvisoryboard.org.au/

- Helping You and Your Family (ACD)

‘Helping You and Your Family’ provides information, support and advocacy for parents and children with a disability in Victoria. The booklet is available in several community languages and is free for families.

http://www.acd.org.au/information/helpb.htm

## Respite

At times parents may require respite and a break from the challenging demands of caring for their child with an ASD. Extended family members such as grandparents are sometimes able to assist with caring for a child for a few hours, overnight or a weekend. This is important as parents may need time out to look after their own needs and to care for their own physical and mental health to enable them to provide optimum care for their child. Not all families have extended family support; however, there are programmes that provide respite services for families of children with a developmental disability.

Respite support is when parents/carers can take a short-term or time-limited break while someone else supports the person with a disability. Respite services aim to provide a positive experience for both the person with a disability and the parent/carer. Respite support can include community participation, in-home support or out of home support.

- Respite Victoria

Respite Victoria has been established as part of the Victorian Department of Human Service's initiatives to improve access to information about respite for carers and people with a disability in Victoria. Respite Victoria has links to the 8 regional disability respite websites in Victoria. Each regional website links you to the Respite Service Search (local and state-wide), and has specific local information, news and events.

http://www.respitevictoria.org.au/what-respite

- Carers Victoria

Carers Victoria work closely with government and other support organisations to improve the lives of caring families throughout Victoria.

http://www.carersvictoria.org.au/

## Sibling support

The sibling relationship lasts longer than all other human relationships and is the focus of research interest in the general population, as well as when a sibling has a developmental disability such as an ASD. The research findings on the impact of having a sibling with an ASD vary considerably. This may be due to the lack of consistency in research measures, with some studies using parent report, others using self-report, and most using a single type of respondent (Macks & Reeve, 2007).

Some studies have found that the presence of a sibling with an ASD may not be considered a risk-factor for adjustment problems among typically developing siblings (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2011). Other studies have suggested that siblings of individuals with an ASD and may even have enhanced psychosocial and emotional development (Kaminsky & Dewey, 2001; Macks & Reeve, 2007). However, other studies report that siblings experience higher levels of internalising behavioural problems and lower levels of prosocial behaviour when compared to siblings of typically developing children or those with other developmental problems (Hastings, 2003; Ross & Cuskelly, 2006) with an increasingly unfavourable impact on the non-disabled sibling as demographic risk factors, such as socio-economic status or number of siblings increased (Macks & Reeve, 2007) also reported. They also suggested that parents have markedly different views from the non-disabled sibling regarding the ways in which siblings' psychosocial and emotional adjustment are affected by the children with autism (Macks & Reeve, 2007). Petalas, Hastings, Nash, Lloyd and Dowey (2009) concurred with earlier studies in their findings that siblings of children with autism had an increased risk of emotional problems, and they also found that these problems persisted over time.

While the findings on the impact of having a sibling with an ASD are inconsistent, what is clear is that siblings are known to have a substantially elevated risk of also having a diagnosis, with evidence of cases of autistic disorder among siblings ranging from 2-6% (Newschaffer et al., 2002). Recent data from prospective studies of developmental trajectories of very young siblings of children with autism indicate strong evidence of early difficulties in cognitive and language development and in social engagement (Elsabbagh & Johnson, 2007; Gamliel, Yirmiya, Jaffe, Manor & Sigman, 2009; Orsmond & Seltzer, 2007; Yirmiya & Ozonoff, 2007).

Sibling relationships change over time in the general population as each sibling moves through different life stages. The symptoms of ASDs also change over time, which may have further implications on the sibling relationship. Clearly, the needs of siblings must be considered in intervention programmes. Siblings need developmentally appropriate information and support. There are siblings support groups and information available through local and state-wide services, including online social-networking sites.

- Association for Children with a Disability

Provides a range of factsheets, booklets and access to local sibling support programmes.

http://www.acd.org.au/siblings/indexb.htm

- Sisters Individuals Brothers (SIBS)

Information and resources for primary school aged and adolescents with a brother or sister with a disability or chronic illness.

www.sibs.org.au

- The Royal Australian and New Zealand College of Psychiatrists (RANZCP)

The Royal Australian and New Zealand College of Psychiatrists (RANZCP), through the work of its Faculty of Child and Adolescent Psychiatry (FCAP), has recently published a position statement:  Addressing the needs of siblings of children with disability or chronic illness.

http://www.ranzcp.org/policy-advocacy/addressing-the-needs-of-siblings-of-children-with-disability-or-chronic-illness.html

## Financial Support

Families of children with an ASD are reported to have greater financial burden compared with other children with special health care needs (Jabrink, Fombonne & Knapp, 2003; Kogan et al., 2008). In particular, Kogan et al. (2008) found that parents report the need for additional income for their child's care and are more likely than parents of children with other health care needs to reduce or stop work due to their child's disability Parent/carers of an adolescent with an ASD can access ;financial support through:

- The Carer Allowance (Centrelink) ph: 13 27 17

The Carer Allowance (not means tested) assists parents of a child with a disability financially and can be applied for through Centrelink. The Carer Allowance Medical Report can be completed by a range of health professionals. Individuals who have not yet received a diagnosis may also be eligible and can apply for the allowance. Centrelink Carer Allowance payments cease when a child turns 16. A new claim for Carer allowance (adult) needs to be submitted as the payment change does not happen automatically. Centrelink provides a range of payments for people with a disability over the age of 16, however not all individuals with an ASD will be eligible. Contact should be made with a Centrelink Customer service Officer prior to the young person's 16th birthday.
http://ww.centrelink.gov.au/internet/internet.nsf/forms/ci002.htm

- Disability Support Pension (Centrelink) ph: 13 27 17

Disability Support Pension is a payment for individuals whose physical, intellectual or psychiatric impairment prevents them from working of retaining work for two years or more.
http://ww.centrelink.gov.au/internet/internet.nsf/forms/ci002.htm

- Chronic Disease Management Plan (Medicare)

The Chronic Disease Management Plan (CDMP) provides five sessions with an allied health professional per calendar year and funding for dental treatment. The CDM plan can be written by a GP.
http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement

- Mental Health Care Plan    (Medicare)

Medicare rebate through a Mental Health Care Plan provides six sessions with an allied health professional. An additional four session may also be available in exceptional circumstances. Ten group sessions with an allied health professional are also available.  This is available for the individual with an ASD, parents, siblings and carers who may need help with their mental health and wellbeing.

http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-b-better

## Advocacy

- National Disability Advocacy Program (NDAP)

The National Disability Advocacy Program (NDAP) provides individuals with a disability access to advocacy to promote, protect and ensure their full and equal enjoyment of all human rights enabling community participation. NDAP disability advocacy agencies receive funding and comply with the *Disability Services Act* and the applicable *Disability Services Standards*.

http://www.fahcsia.gov.au/sa/disability/progserv/providers/NationalDisabilityAdvocacyProgram/Pages/NationalDisabilityAdvocacyProgram.aspx

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Throughout Victoria. Clients may come from any non-English background and may come from any age, gender, or religion. The role of the Advoacy Program is to work in partnership with our clients to achieve goals that meet their individual needs and to ensure equity of access and participation in the community.

http://www.adec.org.au/advocacy.html

- National Autistic Society (NAS)

In consultation with adults who have autism and parents, the NAS has developed an Alert Card, designed to tell people about the condition and asking them to show respect and tolerance. The Alert Card is available in many community languages. Note: the contact details on the card are for UK services.

http://www.autism.org.uk/

- The Youth Disability Advocacy Service (YDAS)

YDAS works alongside young people with disabilities between the ages of 12 and 25 to raise awareness of their rights and to support them to achieve what they want. YDAS provides individual advocacy and also works on broader social issues affecting young people with disabilities through systemic advocacy. This broader work is directed by the YDAS steering committee whose membership is made up exclusively of young people with a range of disabilities from across Victoria. YDAS is a service of the Youth Affairs Council of Victoria funded by the Office for Disability.

http://www.ydas.org.au/

- Victorian Advocacy League for Individuals with Disability Inc. (VALID) ph. 9416 4003

Advocacy support for adults with an intellectual disability. Professional information, education & support

www.valid.org.au

- Disability Advocacy Resource Unit (DARU)

DARU is a statewide service established to resource the disability advocacy sector in Victoria. The resources that DARU provides aims to support the Disability Advocacy sector and Disability Advocates through disseminating relevant and up to date information, organising forums around the state so that there is a coordinated approach to issues of concern, providing professional development opportunities and undertaking capacity building projects on behalf of the sector

http://www.daru.org.au/

## Professional information, education & support

There is an increasing range of education and supports for professionals working in Victoria with primary school students with an ASD and their families. These include specific workshops for teachers and aides, certificate courses, scholarship programs, as well as ‘communities of practice’ and on-line factsheets and resources.

DEECD ASD Coaches

| **New Region** | **Former Region** | **Name** | **Contact Details** |
|---|---|---|---|
| North-Eastern-Victoria | Eastern Metro<br>Hume | Heather Mosley<br>Sue Alexander | mosley.heather.e@edumail.vic.gov.au<br>alexander.susan.s@edumail.vic.gov.au |
| | | | |
| North-Western Victoria | Loddon Mallee<br>Northern Metro | Paul Keller<br>David Ward | keller.paul.j@edumail.vic.gov.au<br>ward.david.j@edumail.vic.gov.au |
| | | | |
| South-Eastern Victoria | Gippsland<br>Southern Metro | Wendy Holcombe<br>Cecelia Morales | holcombe.wendy.m@edumail.vic.gov.au<br>morales.cecilia.a@edumail.vic.gov.au |
| | | | |
| South-Western Victoria | Barwon South West<br>Grampians<br>Western Metro | Sally Midwood<br>Chris Grigg<br>Michelle Savage | midwood.sally.s@edumail.vic.gov.au<br>grigg.chris.c@edumail.vic.gov.au<br>savage.michelle.m@edumail.vic.gov.au |

- Training for integration aides in schools

The Autism Teaching Institute (ATI) has been engaged by DEECD to facilitate educational workshops. ‘Window into Autism ‘is a professional learning opportunity for integration aides who want to understand more about ASDs and improve outcomes for the students.

http://www.education.vic.gov.au/proflearning/sso/asd.htm

- Teacher scholarships

The Special Education Scholarship scheme supports current teachers in Victoria seeking to complete an endorsed special education qualification, including specialist areas such as ASDs.

http://www.education.vic.gov.au/hrweb/careers/teach/scholarships.htm

- Autism Teaching Institute (ATI)

In 2006, DEECD established the Autism Teaching Institute (ATI) based at Western Autistic School. The ATI provides accredited training courses and professional development to build teacher and allied health skills and knowledge about students with an ASD.

http://www.autismteachinginstitute.org.au/

- Positive Partnerships

The ‘Positive Partnerships’ project is coordinated by Australian Autism Education and Training Consortium (AAETC). ‘Positive Partnerships’ provides professional development for teachers and other school staff.. Workshops incorporate an Online Learning Portal where teachers can access learning modules, resources, fact sheets, workshop content and support material.

http://www.autismtraining.com.au/public/index.cfm

- Amaze (Autism Victoria)workshops, courses and information

Amaze Knowledge delivers a range of structured and personalized education courses for services involved in supporting individuals and families with an ASD. They also have a certified training course and arrange speakers for conferences and special events.

http://www.amaze.org.au/discover/how-we-can-help-you/learning-education/

- Working with individuals with an ASD.  Amaze (Autism Victoria)

Amaze has is specific information for the Medical & Allied Health Professionals, Schools, the Emergency Services and for those Working in the Justice System

http://www.amaze.org.au/discover/working-with-individuals-on-the-spectrum/

- National Disability Advocacy Program (NDAP)

The National Disability Advocacy Program (NDAP) provides individuals with a disability access to advocacy to promote, protect and ensure their full and equal enjoyment of all human rights enabling community participation. NDAP disability advocacy agencies receive funding and comply with the *Disability Services Act* and the applicable Disability Services Standards.

http://www.fahcsia.gov.au/sa/disability/progserv/providers/NationalDisabilityAdvocacyProgram/Pages/NationalDisabilityAdvocacyProgram.aspx

- Communities of Practice

Case Consultation Practitioners are employed by DHS in each region across Victoria. They are responsible for providing secondary consultation to disability case managers and developing or building on existing local networks to enhance linkages and pathways. They have also created' communities of practice 'to provide a means of continual learning and development for disability services staff.  Case consultant practitioners are based at various organisations across Victoria.

| REGION | ORGANISATION | EMAIL |
|---|---|---|
| **North/West** | Autism Vic. | www.amaze.org.au/learning |
| **South** | Windermere | www.windermere.org.au |
| **East** | Autism Vic. | www.amaze.org.au/learning |
| **Hume** | Mansfield Autism Statewide Services | www.autismmansfield.org.au |
| **Loddon-Mallee** | Community Living & Respite Services Inc. | www.clrasd.org.au |
| **Gippsland** | SCOPE | https://sites.google.com/site/autismgippsland/ |
| **Barwon S-W** | Gateways<br>MPOWER | www.gateways.com.au<br>www.mpower.org.au |

- Action on Disability in Ethnic Communities (ADEC)

ADEC has an education unit that involves:

- assisting organisations promote the provision of culturally relevant services within disability, child and aged care and primary health services.
- promoting knowledge and information of disability, child and aged care and primary health services within ethnic communities.
- providing education and training to people with disabilities to gain the skills required for further education and employment.
- Providing education and training to people who wish to gain the skills required for further education and employment in the disability, aged care and primary health services area.

http://www.adec.org.au/

- Regional Autism Consultation and Training Teams (ReACTs) or
  Regional Autism Planning Teams (RAPT)

These teams identify and respond to the regional ASDs training and consultation needs.

| REGION | COORDINATORS | EMAIL |
|---|---|---|
| North | Priscilla Parodi | parodi.priscilla.p@edumail.vic.gov.au |
| South | Cecilia Morales | morales.cecilia.a@edumail.vic.gov.au |
| East | Anne Kettle | kettle.anne.t@edumail.vic.gov.au |
| West | Anne Butterworth | butterworth.anne.a@edumail.vic.gov.au |
| Hume | Jenny Drysdale | drysdale.jennifer.m@edumail.vic.gov.au |
| Grampians | Desley Beechley | beechey.desley.j@edumail.vic.gov.au |
| Loddon-Mallee | Angela Walsh-Edgar | walsh-edgar.angela.t@edumail.vic.gov.au |
| Gippsland | Naomi Licciardello | Licciardello.naomi.w@edumail.vic.gov.au |
| Barwon South-West | Jann Kirkland | Kirkland.jann.e@edumail.vic.gov.au |

- Autism Spectrum Australia (Aspect)

Autism Spectrum Australia (Aspect) provides a Positive Behaviour Support Program for children and young people (aged 6-25 years) with an ASD. The programme offers three levels of support.

1. Parents can access free Positive Behaviour workshops designed to support and assist families, carers and others to develop a greater understanding of the individual with ASD and the impact that this has upon learning, behaviour and development, and to design and implement an individualised positive behaviour support plan based upon an identified behaviour of concern.

2. Families of clients who require support at a more intensive level can participate in these workshops, but will be able to apply to receive individualised support to define specific goals and to design and implement a detailed behaviour support plan in the home and in other settings (including schools). Additional training and support can be provided to local services.

3. The highest intensity of support is longer term and designed to address issues with people who have more complex needs and enduring challenges. Clients requiring this level of support may be at significant risk of family breakdown or loss of school placement.

http://www.autismspectrum.org.au

- Evidence-based practice and autism in the schools: A guide to providing appropriate interventions to students with ASDs' (2011).

This manual is a valuable guide for teachers that provides an outline of ASDs, summarises the research findings from the national standards report, describes the importance of professional judgment, and the values and preferences of families in evidence based practice.

http://www.nationalautismcenter.org/index.php

- Alpha Autism

Alpha Autism Consultancy Services assist workplaces with developing tailored training solutions.

http://www.alpha-autism.org.au/

- National Autistic Society (NAS)

The NAS has a comprehensive website that includes a section for adults with an ASD. Useful resources include printable tip sheets on topics such as making friends and telling people that you have an ASD.

http://www.autism.org.uk/

- Inclusion Online course: Understanding Autistic Spectrum Disorder

The Inclusion Online courses are an online learning portal that are available across Victorian government schools, and free to all teachers from government schools. The course is held over a ten week period requiring approximately two hours online participation per week. Course participants are supported by an online tutor and study alongside up to 12 colleagues. Although the course is delivered online, there are three one-hour face to face sessions occurring over the ten weeks.

http://www.pd-online.com.au

# Other considerations (Adolescence)

## Health

ASDs are not degenerative disorders. However, associated medical conditions such as epilepsy or accidents related to significant ID have been reported to be related to early deaths (Shea & Mesibov, 2005). Whilst some studies have reported a significantly higher death rate for individuals with PDDs than the expected mortality rate (Mouridsen, Bronnum-Hansen, Rich, & Isager, 2008; Shavelle et al., 2001) the vast majority of individuals with and ASD live at least through middle age and beyond. Some reports suggest that individuals with autism and ID have fewer of the risk factors such as smoking and alcohol consumption that are associated with typical adult lifestyles (Shavelle et al., 2001).

There is a known association between autism and epilepsy with prevalence rates of epilepsy in those with autism varying from 5% - 40% compared to the general population of .5% - 1% (Amiet et al., 2008). The risk for epilepsy in autism is higher for girls and for individuals who also have an intellectual disability (Amiet, et al, 2008) and also for those who have had a traumatic birth (Larson et al., 2005). Peak periods of seizure onset are reported to be in early childhood and adolescence (Tuchman & Rapin, 2002).

- The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health (CDDH) strives to improve the health and healthcare of people with a disability by enhancing the capacity of mainstream health services through educational activities, research projects, clinical services and advocacy initiatives. CDDH run sessions for professionals involved in the healthcare of people with developmental disabilities. They conduct consultancy and research clinics, as well as clinical services for people with developmental disability.

http://www.cddh.monash.org/

- Annual Health Assessment (Medicare)

All patients with an intellectual disability are eligible for an annual health assessment (one per patient in any 12 month period). This is an evidence based service funded by the Medicare Benefits Schedule (MBS), which recognises that the health needs of patients with an ID are often unrecognised.

The annual health assessment provides an opportunity for the GP to identify and manage any health problems as well as to undertake disease prevention. Patients (or their carers) might request a health assessment or they may be identified by the practice when they present in relation to another matter or through practice audit. Prior to attending for a health assessment, the patient’s carer will often provide the GP with a Comprehensive Health Assessment Program (CHAP). The CHAP is a health assessment tool which provides information about the patient’s past history and guides the GP through the health assessment by prompting the GP to be aware of commonly missed, difficult to manage or syndrome specific health conditions for patients with an intellectual disability. It is the GPs decision whether to use CHAP or not.

Completion of the annual health review usually includes review of medications, preventive health measures, detection of co-morbidity, and identification of risk factors and management of active health needs. Findings may prompt further investigation or referral, or development of a GP Management Plan/Team Care Arrangements.

http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-qandaintelldisability

## Mental Health

Children and young people with an ASD are at risk of significantly higher levels of emotional and behavioural problems compared to their typically developing peers, and also those with an ID (Bradley et al., 2004; Brereton, Tonge & Einfeld, 2006; Lainhart & Folstein, 1994; Smalley, McCracken & Tanguay, 1995; Steinhausen & Metzke, 2004). Emotional and behavioural problems (psychopathology) in toddlers, children and adolescents with ASDs has been found to contribute to maternal stress and parental mental health problems (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Hastings et al., 2005; Herring et al., 2006; Lecavalier, Leone, & Wiltz, 2006; Tonge & Einfeld, 2003).

Individuals with autism have been found to be at risk of developing a new psychiatric disorder by adult life (Hutton, Goode, Murphy, LeCouteur & Rutter; 2008). All types of psychiatric disorders occur in individuals with an ASD (Ghaziuddin, 2005; Hutton et al., 2008) and they present with more psychiatric symptoms or disorders than the general population (Bradley et al., 2004; Bradley et al., 2007; Gadow et al., 2004; Gillberg & Billstedt, 2000; Leyfer et al., 2006; Simonoff et al., 2008; Tonge & Einfeld, 2003). Psychiatric disorders can also be multiple in those with an ASD (Simonoff et al., 2008). These primarily include anxiety disorders (Fombonne, 1992; Gillot, Furniss & Walter, 2001; Nick, Szatmari, Bryson, Streiner & Wilson, 2000; Simonoff et al., 2008) depression and other mood disorders (Bradley et al., 2004; Brereton et al., 2006; Lainhart & Folstein, 1994; Ghaziuddin, Ghaziuddin & Greden, 2002; Tonge & Einfeld, 2003) and symptoms of ADHD (Goldstein & Schwebach, 2004; Nick et al., 2000; Loveland & Tunali-Kotoski, 1997; Rinehart & Tonge, 2007; Simonoff et. al., 2008).

Accurate diagnosis of comorbid psychiatric conditions in young people with an ASD is critical as the comorbid disorder may cause significant impairment and additional burden of illness on the young person and their family, and requires specific treatment (Leyfer et al., 2006). While comorbid psychiatric symptoms in those with an ASD is now well described in the literature, infrequent identification and diagnosis may be due to diagnostic overshadowing in which the psychiatric symptoms are attributed to the ASD or ID (Simonoff et al., 2008). The impact of comorbid mental health problems on the long-term adjustment, wellbeing and outcome for individuals with an ASD is still unclear. Whilst intellectual functioning and early language development are found to have been the most significant factors determining outcome (Howlin et al., 2004; Howlin, 2005), there has not been systematic investigation on the role of comorbid psychiatric disorders (Ghaziuddin, 2005). There is evidence of increased genetic vulnerability to a range of mental health problems, such as the association with familial depression (Bolton, Pickles, Murphy & Rutter, 1998; Piven & Palmer, 1999), bipolar disorder (DeLong & Dwyer, 1988) and ADHD (Goldstein & Schwebach, 2004; Reierson, Constantino, Volk & Todd, 2007).

### Anxiety

Anxiety disorders differ from fears and worries,( which are common in individuals with an ASD), in the level of severity, associated distress and life interference. Studies report high rates of anxiety disorders in individuals with an ASD (Fombonne, 1992; Gillot et al., 2001; Nick et al., 2000; Simonoff et. al., 2008). In addition to generalized anxiety disorder, individuals with an ASD can also develop distinct anxiety disorders such as obsessive compulsive disorder and post traumatic stress disorder (Ghaziuddin, 2005). Symptoms of anxiety, (e.g. fears, resistance to change, panic, phobias, tenseness, shyness, irritability and somatic symptoms) cause distress and impairment for the individual, but also have the potential to disrupt education, further impair social interaction and create management problems and stress for the parents and carers. Individuals with symptoms of anxiety may respond to cognitive and behavioural treatment approaches and also to pharmacological treatments (Tonge & Einfeld, 2003).

### Depression & other mood disorders

Mood disorders, including depression, are the most common psychiatric disorder occurring in the general population (Ghaziuddin, 2005), characterised by depressed mood, irritability, sleep and appetite disturbance, obsessional thoughts, lethargy and a loss of enjoyment or pleasure in normally enjoyable activities. Individuals with an ASD are at increased risk of suffering depression and mood disturbance (Bradley et al., 2004; Brereton et al., 2006; Lainhart & Folstein, 1994; Ghaziuddin, Ghaziuddin & Greden, 2002; Sterling, Dawson, Estes & Greenson, 2008; Tonge & Einfeld, 2003) probably due to both biological and environmental factors (Brereton et al., 2006). Whilst prevalence is not known, studies suggest that it is the most common psychiatric disorder seen in individuals with an ASD, but can be difficult to diagnose in those with severe cognitive and communication impairment (Ghaziuddin, 2005). Those individuals with an ASD suffering from depression often display an exacerbation of symptoms, such as social withdrawal and an increase in obsessive compulsive behaviours. They may also display a change in character of their obsessional interests and activities, irritability, sadness, aggression or a regression in skills (Ghaziuddin, 2005).

Children with autism are more likely to have a family history of depression (Ghaziuddin & Greden, 1998). In particular, mothers of children with autism are more likely to suffer from depression than mothers of children with an I.D. without autism and also mothers of typically developing children (Bristol, Gallagher & Holt, 1993; Olsson & Hwang, 2001; Piven & Palmer, 1999; Wolf, Noh, Fisman & Speechley, 1989; Yirmiya & Shaked, 2005). Individuals with an ASD may respond to psychological treatments such as cognitive therapy, relaxation training, and pleasant events scheduling, as well as pharmacological treatment for severe or persistent depressive symptoms.
; Reiersen & Todd, 2008).

- Victorian Dual Disability Service (VDDS)

The Victorian Dual Disability Service is a state-wide mental health service for people with an intellectual disability. In Victoria the term Dual Disability is used to describe people with an intellectual disability who also have a mental health problem. VDDS provides clinical support and training and has some valuable publications on a range of issues. Clinical support includes the provision of advice to anyone about the mental health of people with an ID in relation to:

- Assessment for an ASD
- Presentation of mental disorders
- Mental health assessment
- Treatment for a mental disorder
- Management of mental and behavioural disorders
- Services available in Victoria and how to access these services

http://www.svhm.org.au/services/VictorianDualDisabilityService/Pages/VictorianDualDisabilityService.aspx

- The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health (CDDH) strives to improve the health and healthcare of people with a disability by enhancing the capacity of mainstream health services through educational activities, research projects, clinical services and advocacy initiatives. CDDH run sessions for professionals involved in the healthcare of people with developmental disabilities. They conduct consultancy and research clinics, as well as clinical services for people with developmental disability.

http://www.cddh.monash.org/

- Child and Adolescent/Youth Mental Health Services (CAMHS/CYMHS)

In Victoria, specialist child and adolescent mental health services (CAMHS) respond to those experiencing more complex and severe mental health problems. CAMHS also play a lead role in promoting quality mental health responses in other sectors.

http://www.health.vic.gov.au/mentalhealth/camhs/

- Developmental Behaviour Checklist (DBC)

The Developmental Behaviour Checklist (DBC) measures emotional and behavioural problems in children and young people (4-18 years) with developmental disabilities. There is both a 96 item parent-completed questionnaire (DBC-P) and a teacher version of the DBC (DBC-T) which allows educators to provide valuable additional information about the child or young person in a school setting. The DBC-P (parent) has been translated into other languages including Arabic, Chinese, Croatian, Dutch, Finnish, French, German, Greek, Hindi, Italian, Japanese, Malay, Norwegian, Portuguese, Portuguese (Brazil), Spanish, Swedish, Turkish and Vietnamese. The DBC-T (teacher) has been translated into Spanish, Dutch, French and Finnish.

The Developmental Behaviour Checklist (DBC-A) is a 107 item instrument for the assessment of behavioural and emotional problems of adults with developmental and intellectual disabilities and is completed by family members or paid carers who know the person well. It can be used in clinical practice in assessments and monitoring interventions, and in research studies. The DBC-A has been translated into Dutch, Finnish and French.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

## Sexuality & relationships

Sexuality is an integral part of human development and includes gender, sexual identity, reproduction and sexual orientation (Jones & Chivers, 2011). Whilst there is a limited literature on issues of sexuality and relationships of people with ASDs, there is no doubt that it is an important issue. The broader literature on people with developmental disabilities indicates that the information and support people with a disability have influences their sexual health, their ability to make informed decisions, develop relationships and remain safe. Furthermore, lack of support may lead to exploitation, vulnerability to abuse, poor health and contact with the criminal justice system (Jones & Chivers, 2011).

Several studies have found that the majority of adolescents and young adults with an ASD express sexual interest and have a variety of sexual behaviours (Hellemans et al., 2007; Hellemans et al., 2010; Konstantareas & Lunsky, 1997). Adolescents with an ASD usually have to learn about social skills and relationships without the opportunity of peer group discussion and support available to typically developing adolescents (Howlin, 2005). Furthermore, individuals with an ASD have been found to show more difficulties with the external changes of the body during puberty (Hellemans et al., 2010). The complexity of developing and maintaining intimate and sexual relationships can be perplexing for adults with an ASD. Difficulties with understanding social relationships and interactions, problems with developing empathy for others' and intense interests, non-functional routines and rituals can all lead to misunderstanding and confusion.

Jones and Chivers (2011) identified a number of elements to sexual education for young people with learning difficulties. Many of these are also pertinent to those with an ASD and include:

- information about the changing bodies and integrity of their body
- rules about social sexual behaviour
- a safe environment
- support in developing positive sexuality
- skills in developing and maintaining friendships
- opportunities to develop intimate relationships
- opportunities to take risks to enable independence
- access to health services
- advocacy (p 195).

- The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health provides a range of supports and services related to children, adolescents and adults with a developmental disability and sexuality. This includes educational counselling to individuals and couples with developmental disability, sexual knowledge assessments and identification of human relations needs, education sessions for people with developmental disability, staff, parents/carers, professional and community organisations, telephone consultation, tertiary consultations. They also provide human relations educational materials.

http://www.cddh.monash.org/sexuality-disability.html

- Amaze (Autism Victoria) factsheet: Romantic Relationships and ASD

http://www.amaze.org.au/uploads/2011/08/Fact-Sheet-Romantic-Relationships-ASD-Aug-11.pdf

## Guardianship and legal concerns

Like all young adults who turn 18 years of age, individuals with an ASD are legally entitled to make decisions for themselves. This is the case whether they have an ID or not. This can be surprising and confusing for parents who have cared for their child and been the primary decision maker for many years. However, there are times when parents or other family members are aware that an adult with an ASD may require additional help with making informed decisions about medical or financial issues, or other matters of daily life. The Victorian Civil and Administrative Tribunal (VCAT), Office of the Public Advocate (OPA) and State Trustees can provide further information , support and services.

- Victorian Civil and Administrative Tribunal (VCAT)

VCAT is a Tribunal that makes decisions about a range of disputes. It has a number of sections called ‘lists’ that deals with guardianship, administration, powers of attorney and related matters. Applications may include applications for orders such as:

- appointing guardians to make decisions for a person, including accommodation
- appointing administrators to manage a person's financial and legal affairs
- revoking an attorney's appointment, or varying, suspending or making another order in relation to a financial enduring power of attorney under the *Instruments Act* 1958
- revoking or suspending an enduring power of attorney (medical treatment) under the *Medical Treatment Act* 1988
- consenting to a "special procedure". That is, a procedure intended or likely to cause infertility, termination of pregnancy or removal of tissue for transplanting.

VCAT also hears and determines applications under the *Disability Act* 2006 to:

- review decisions by the Secretary to the Department of Human Services to admit a person with an ID to a residential institution
- review decisions about "restrictive interventions" (the restraint or seclusion of a person with a disability)
- make orders about residential treatment facilities, including a resident’s treatment plans and leave of absence

- make orders about "security residents" (persons with an ID transferred from prison to another facility), including a security resident's treatment plans and leave of absence
- make and review supervised treatment orders for persons with an ID if satisfied that, among other things, the person must be detained to prevent serious harm to another person

http://www.vcat.vic.gov.au

- ➢ Office of the Public Advocate (OPA)

The OPA is an independent statutory body that works to protect and promote the interests, rights and dignity of people with a disability. A range of services include:

- Advice and information about matters including powers of attorney, guardianship, VCAT applications and consent to medical and dental treatment

- Advocate/Guardian program for volunteers who are appointed by the public advocate to act as independent guardians for people with a disability

- Community visitors programme. Volunteers who visit accommodation facilities for people with a disability or mental illness

- Independent third person programme. Volunteers who assist people with an ID or mental illness during interviews or when making formal statements to police

- Education sessions on topics such as enduring powers of attorney and medical consent

http://www.publicadvocate.vic.gov.au/

- ➢ State Trustees

State Trustees is a state owned company that provides a range of services for people who can't manage their own affairs because of their disability. They provide financial and legal assistance including will and executor services and the special disability trust.

http://www.statetrustees.com.au/about-us

## Youth Justice

Although there is a limited research on ASDs and youth justice, there appear to be some emerging trends. The majority of young people with an ASD are law abiding and do not come into contact with the criminal justice system as a victim, witness, suspect or offender. However, individuals with developmental disabilities, including ASDs, are more likely than typically developing individuals to be the victims of crime and/or exploitation (National Research Council, 2001).

Some researchers have suggested that the core features of ASDs, including social naivety, a poor understanding of others' perspectives and restricted and repetitive interests and patterns of behaviour, may contribute to illegal behaviour in individuals with an ASD (Cheely et al, 2011; Mayes, 2003; Woodbury-Smith et al, 2005). It has also been suggested that high rates of comorbid psychiatric conditions in individuals with an ASD may also increase the risk for committing offences and being in contact with the law (Vermeiren et al, 2006). Others have suggested that the very literal and pedantic adherence to rules and the law of those with an ASD make it less likely they will engage in an offence (Howlin, 1997). Haskins and Silva, (2006) suggested that deficits in theory of mind, intense narrow interests and poor interpersonal skills may heighten the risk for engaging in criminal behaviour in individuals with Asperger's Disorder. A study by Scragg and Shah (1994) found that criminality is associated more often with Asperger's disorder than Autism. Haskins and Silva, (2006) suggested that as forensic clinicians are becoming more familiar with the presentation of Asperger's disorder, individuals with Asperger's are over-represented in forensic criminal settings.

Once a young person with an ASD is in the youth justice system, the nature of their difficulties may not be recognised or may be misunderstood. In these circumstances it is possible for miscarriages of justice to occur and it is therefore critical that legal experts are familiar with ASDs. Appropriate support needs to be in place in order that young people with an ASD are understood and appropriately represented.

Some studies also discuss the degree of criminal responsibility in people with ASDs. Because of deficits in empathy, there may be important repercussions when assessing remorse in criminal proceedings when the offender has Asperger's Disorder (Haskins & Silva, 2006). Barry-Walsh and Mullen, (2004) presented five case histories of a person with Asperger's disorder who had a history of offending. In each case, the offence was understandable in the context of the disorder and all were "surprised by the reactions their actions evoked in others and had difficulty understanding why they were now facing criminal charges" (p 105).

> "…it behoves us to draw to the courts' attention the obvious: that patients with Asperger's Disorder suffer from mental disorder and that their offending and subsequent disposition must be placed in this context. The core features of Asperger's Disorder and how they determine what the individual knows and understands of the world should form a basis for sophisticated assessment of the issues of disability and legal insanity" (Barry-Walsh and Mullen, 2004, p 106).

Cheely et al., (2011) found that youth with an ASD in the US had higher rates of person offenses such as assault, but lower rates of property offences such as trespassing. Cheely et al., (2011) also found that young people with an ASD and an ID were significantly less likely to be charged with an offence than comparison groups. Young people in the Cheely et al. (2011) study were also more likely to be diverted into pre-trial intervention and less likely to be prosecuted than others. However, some researchers have found that adolescents and young adults with an ASD may be over-represented in the criminal justice system, as victims, witnesses or perpetrators. However, some studies have found low prevalence rates of individuals with an ASD in youth detention centres (Browning & Caulfield, 2011; Cheely et al., 2011). Clearly much research is still needed.

Howlin (2003) suggests that whilst approaches to intervention must be individualised, an emphasis must be placed on early intervention with an understanding that behaviours that appear innocuous in a young child take on a different perspective in an adult (e.g. hugging unfamiliar adults when greeting them). Howlin emphasises the need to establish consistent rules and provide appropriate social skills training.

- Autism: a guide for criminal justice professionals (National Autistic Society )

A practical guide for criminal justice professionals in the UK who may come into contact with an ASD as victims, witnesses, suspects or offenders. It is based on the experiences of people with an ASD and those who work with them, and contains real-life examples and personal accounts by professionals. Much of the guide is also useful in an Australian context.

http://www.autism.org.uk/working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx

## Cultural awareness

Culture is “the shared way of life including attitudes, beliefs, norms and values of people” (Powie, 2012, p. 63).There are inevitable stressors for people who are adapting to a new country, culture, social system and language. Families from culturally and linguistically diverse (CALD) backgrounds may experience stressors due to settlement issues, trauma, pre-post immigration experiences, unemployment, limited social support and poverty (Baasiri & Carroll, 2011). There may be additional cultural complexities to the adjustment and wellbeing of individuals with a disability, including those with an ASD, and their families. Cultural differences in family members’ responses to disability have been reported to influence levels of stress and long-term outcomes (Echemendia & Westerveld, 2006).

Cultural awareness and sensitivity is important in the fields of disability and mental health. Baasir & Carroll (2011) stated that “Clinicians need to adjust the way they provide health and mental health services, using knowledge of the culturally mediated values, attitudes, and experiences that apply to a given case, and through effective communication skills, and a willingness to advocate on behalf of families” (p. 44).

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Clients may come from any non-English background and may come from any age, gender, or religion.

http://www.adec.org.au/advocacy.html

- Cultural Diversity Plan for Victoria’s Specialist Mental Health Services (DoH)

The Cultural Diversity Plan for Victoria’s Specialist Mental Health Services provides a framework for improving the accessibility and responsiveness of mental health services to Victoria’s CALD communities. The Cultural Diversity Guide identifies a range of strategies to improve cultural responsiveness and provide high quality service provision. It provides examples of good practice, as well as guidance on additional resources and supports to respond to diversity for programs and agencies.

http://www.health.vic.gov.au/diversity/cald.htm

- The Transcultural Mental Health Access Program (ADEC)

ADEC works with ethnic communities to raise awareness about mental health problems and ways to access mental health and carer services, assists mental health services with developing culturally responsive models and strategies of working with ethnic communities and works with community and ethno-specific organisations to raise their awareness of the impact of mental illness on ethnic communities and ways of assisting their clients to better access appropriate mental health services.

http://www.adec.org.au/index.php/services/mental-health

- Victorian Transcultural Psychiatry Unit

The Victorian Transcultural Psychiatry Unit (VTPU) is a state-wide unit which supports area mental health and psychiatric disability support services in working with CALD consumers and carers throughout Victoria.
http://www.vtpu.org.au/links/

# SECTION SIX

## Adulthood (The post school years)

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**Assessment & Diagnosis**

# Assessment & Diagnosis (Adulthood)

## Assessment in the adult years

Most individuals with an ASD receive their diagnosis during their childhood years. In some cases, a diagnosis is not given until adulthood. This may be because the disorders were not recognized when they were children. For example, Asperger's syndrome was initially described by Hans Asperger in 1944, but not translated from German to English by Uta Frith until 1991. A late diagnosis may also be due to changes in diagnostic criteria, as some individuals who would now meet criteria for an ASD may have previously misdiagnosed or not diagnosed at all (Geurts & Jansen, 2012).

Diagnosis of an ASD in adulthood was extremely rare until recent years. However, in more recent times there is wider recognition that a diagnosis of an ASD may lead to providing understanding and support to individuals, family members and professionals. An assessment in the adult years may arise when the individual has been diagnosed with another disorder in childhood or adolescence such as an intellectual disability or a mental illness. A parent, carer or professional may observe characteristics consistent with an ASD and recommend an assessment. Alternatively, the individual may have struggled for many years with feeling "different" to other people and seek an assessment. Sometimes when a child receives a diagnosis of an ASD, parents and family members learn more about the disorder and may identify with characteristics associated with ASDs. This may lead to an assessment and diagnosis for them.

## Assessment services

There are currently no publicly funded adult ASD assessment clinics in Victoria. Therefore, adults seeking an assessment typically consult with a psychologist and/or adult psychiatrist who has experience in ASDs. Other professionals such as an occupational therapist or speech pathologist may also be involved in the assessment.

Comprehensive assessment should always include expert clinical judgment combined with a range of valid and reliable standardized instruments. Currently, the international classification standard for establishing a diagnosis of autism and other pervasive developmental disorders is outlined in both the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition, Text Revised, of the American Psychiatric Association (DSM-IV-TR) (APA, 2000) and the International Classification of Diseases and Related Health Problems (ICD-10) (WHO 1992). In Victoria, the DSM-IV-TR (APA, 2000) is used.

- Victorian Dual Disability Service (VDDS)

The VDDS provides phone-based advice to anyone about the mental health of people with an intellectual disability in relation to assessment for ASDs. Advice is also provided in relation to presentation of mental disorders, mental health assessment, treatment for a mental disorder, management of mental and behavioural disorders, and services available in Victoria and how to access these services.

http://www.svhm.org.au/services/VictorianDualDisabilityService/Pages/Clinical.aspx

## ASD assessment guidelines

ASDs are complex disorders and undertaking an ASD assessment requires a rigorous, comprehensive and systematic approach. Professionals involved in ASD assessments require training, experience and supervision. In Victoria, ASDs assessment guidelines have been developed by Autism Victoria (2009). The 'Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders' provide a definition of ASDs, outline assessment standards and guidelines, and list eligibility criteria for government funding services. The guidelines advocate a multi-disciplinary approach to assessment using DSM-IV-TR criteria.

- Autism Victoria's Diagnostic Process for Children, Adolescents and Adults Referred for Assessment of Autism Spectrum Disorders

http://www.amaze.org.au/uploads/2010/11/ASD-Diagnosis-Assessment-Guidelines-Victoria.pdf

Components of diagnostic assessment for adults may include:

- Comprehensive developmental and family history
- Medical assessment
- Psychiatric/mental health examination
- Review of educational, social, employment and home environments
- Interview with other relevant professionals
- Cognitive assessment (Wechsler Adult Intelligence Scale (WAIS-IV)
- Assessment of adaptive functioning (VABS-II)
- Assessment of speech/language

- Adult specialist mental health services (16-64 years)

Adult specialist mental health services are aimed primarily at people with serious mental illness or mental disorder who have associated significant levels of disturbance and psychosocial disability due to their illness or disorder. Commonly these will be people with a diagnosis of a major mental illness, such as schizophrenia or bipolar disorder, but will also include some people with other conditions such as severe personality disorder, severe anxiety disorder, or those who present in situational crisis that may lead to self-harm or inappropriate behaviour towards others. The distinguishing factor is the level of severity of the disturbance and impairment.

http://www.health.vic.gov.au/mentalhealth/services/adult/

- Mindful: Centre for Training and Research in Developmental Health

A training program in assessment, diagnosis and treatment for practitioners has been funded by the Department of Health and designed and delivered by Mindful: Centre for Training and Research in Developmental Health, University of Melbourne. Regular training is provided on the fundamental of ASDs assessment and diagnosis and is enhanced by follow-up seminars on assessment and treatment for adolescents and young adults, and workshops on specific ASD assessment instruments (e.g. ADOS-2).

http://www.mindful.org.au/Home.aspx

# Intervention & treatment (Adulthood)

While there has been a research focus on children with an ASD over the past several decades, there is a dearth of research on the psycho-educational needs and interventions for adults with an ASD. As the aetiology of ASDs has not yet been determined in the majority of cases, there is no specific treatment for these complex neuro-developmental conditions. Francis (2005) stated that, as there is "…no cure at present, the word "treatment" should only be used in a very limited sense, reflecting interventions aimed at helping people with ASD to adjust more effectively to their environment" (p. 493).

## Best practice guidelines

Papers on evidence based treatments and interventions provide important information for individuals with an ASD, parents /carers and professionals to assist them in making informed decisions about appropriate interventions.

### The National Standards Reports

A report from the National Autism Centre (2009) in the USA provided information about the level of scientific evidence that existed in support of educational and behavioural treatments for individuals (0-22 years) with an ASD in the National Standards Report. The report used four levels of strength of evidence (established, emerging, unestablished and ineffective) and was the first to have also provided information about treatment effectiveness based on age, diagnostic group and treatment targets. The National Autism Centre's Standards Report (2009) recommended that parent-professional teams give serious consideration to 'established' treatments, do not begin with 'emerging' treatments, and only consider 'unestablished' treatments after additional research has been conducted and shown favourable outcomes. Further details of each of the interventions can be obtained by reading the report.

Only one ‘established’ treatment was identified for young adults between the ages of 19-21 years: the behavioural package. This package includes interventions designed to reduce problem behavior and teach functional alternative behaviours or skills through the application of basic principles of behavioural change. Treatments falling into this category reflect research representing the fields of applied behavior analysis, behavioural psychology, and positive behavior supports (p. 45).

It is of equal importance for us to be informed about those treatments that are identified as ‘unestablished’. Unestablished treatments are described as those for which there is little or no evidence in the scientific literature to draw firm conclusions about the effectiveness of these interventions with individuals with ASD. The NAC guidelines state that “There is no reason to assume these treatments are effective. Further, there is no way to rule out the possibility these treatments are ineffective or harmful” (p. 70). This is because the quality, quantity, and consistency of research findings have generally been poor or do not apply to individuals with ASD.

The national standards report also identified five treatments that were had an ‘*unestablished’* level of evidence:

- Academic Interventions
- Auditory Integration Training
- Facilitated Communication
- Gluten- and Casein-Free Diet
- Sensory Integrative Package

Furthermore, the NAC guidelines state that:

> “There are likely many more treatments that fall into this category. That is, there are many treatments for which no research has been conducted or, if studies have been published, the accepted process for publishing scientific work was not followed. There are a growing number of treatments that have not yet been investigated scientifically. These would all be Unestablished Treatments. Further, any treatments for which studies were published exclusively in non-peer-reviewed journals would be Unestablished “(p.70).

- National Standards Report (2009)

http://www.nationalautismcenter.org/pdf/NAC%20Standards%20Report.pdf

## Transition to adulthood

The transition from secondary school to the range of post-school options, including tertiary education and employment, is a pivotal time for all young people. It is particularly significant and demanding for those young adults with an ASD. Difficulties may arise for young people with an ASD during this period of transition because of:

- the young adult's ASD symptoms (social, communication, behaviour)
- the individuals thinking and learning style
- difficulties in managing change
- particular difficulties in managing stressful situations
- difficulties in both understanding and using language
- co morbid conditions (health, ID and mental health problems) (Brereton & Bull, 2012).

Currently there is no literature on evidence-based management of transition to post school options for young adults with an ASD. There is however, a growing body of literature on the importance of comprehensive, coordinated, and individualised transition planning. In the US, Federal law requires a transition plan be developed for all young people with an ASD by the age of 16 years, however, most recommendations generally suggest that transition planning should begin no later than age 14.

The Southwest Autism Research & Resource Centre's guide for the transition to adulthood (2006) for adults with autism states that "Effective transition planning always starts with vision: Where will this individual be at the end of this process? What skills will this individual have? What contexts will be the best for him to apply these skills?"

There are a range of issues to be considered throughout the transition planning process including:

- community participation and leisure
- adult services and supports
- tertiary education (including TAFE, University)
- employment
- independent living and accommodation

- 'Life Journey Through Autism: A Guide for Transition to Adulthood' (2006).

The Southwest Autism Research & Resource Center has produced a useful resource designed to give parents, teachers, and other education professionals an introduction to the transition to adulthood. The guide suggests a planned approach to transition is central to more independent, involved, and enjoyable adult lives for individuals with ASDs.

http://www.researchautism.org/resources/reading/documents/TransitionGuide.pdf

- Transition toolkit

Autism Speaks ™ has developed the Transition Tool Kit A guide to assist families on the journey from adolescence to adulthood( 2011). This useful guide provides templates and information on topics such as self-advocacy, rights, employment, accommodation and tertiary education,

http://www.autismspeaks.org/docs/family_services_docs/transition.pdf

- Effective Transition Planning for Secondary School Students with Disability

The Australian Governments (DEEWR) guide to resources for student s with a disability.

http://www.ndcovictoria.net.au/getdoc/a67fd226-0cb4-48a7-ab49-8d40076dffb1/Effective-Transition-Planning-for-Secondary-School.aspx

- Choosing Your Path. Disclosure: It's A Personal Decision ( Department of Industry, Innovation, Science, Research and Tertiary Education)

A web-based resource that addresses the challenges and choices for people with disabilities, employers and educators. The website provides information about options and pathways for individuals with disabilities and on the role and responsibilities of employers and educators.

http://pubsites.uws.edu.au/ndco/disclosure/

## Tertiary Education

### 1. University and Technical & Further Education (TAFE)

Studying at University and TAFE can be an exciting and appropriate option for some young people with an ASD, following secondary schooling. However, there are particular challenges due to the discontinuities between secondary and tertiary education. These include:

- larger number of students
- larger campus
- non compulsory attendance
- lecture and tutorial structure
- less interaction with lecturers
- complexity of timetable and organisational requirements
- lack of structured 9.00-3.30 daily routine
- expectation of independence
- self-directed learning
- distance from home

In 2002, the National Autistic Society prepared guidelines related to the transition to university for students with Asperger's disorder (NAS, pp. 54-55) that are pertinent to the Victorian context for individuals with an ASD. These included the following:

- The student should have the support in order to make the move into college or university
- Students will often require advice about applying for support and asking the right questions before choosing a course
- Form a transition planning group
- Awareness sessions on Asperger's Disorder to be taken up by college/university, for all staff – A 'Systems approach' (reception, tutors, student counsellors...)
- Learning support, counsellors and disability officers will benefit from 'job specific' training on Asperger's Disorder to enable them to provide effective pastoral support.

- A coherent protocol for students entry into college/university including:
    - ✓ enrolment forms with mention of developmental difficulties such as Asperger’s
    - ✓ stress reducing ‘welcomes’ (e.g. prior contact with an personal tutor, home visit)
    - ✓ ensuring funding is in place for any learning support before term starts
    - ✓ good induction and orientation (e.g. maps of the campus and important contacts)
    - ✓ a flexible approach (e.g. allowing visits during holidays for familiarisation)
    - ✓ establishing positive contact with parents, when appropriate.
    - ✓ colleges locally should discuss good practice and share ideas about how best to support students.
    - ✓ colleges should consider Asperger’s Disorder specific courses, ‘open-learning’ or outreach courses to assist those who find traditional provision prevents them from learning.
    - ✓ colleges should consider courses which help prepare people for work, by developing closer links with employers, and which address the specific employment needs of people with Asperger’s Disorder

- Supporting tertiary students with ASD in University and TAFE (LaTrobe University)

LaTrobe University has a useful website with information for university and TAFE students diagnosed with an ASD, their parents, and tertiary staff. The website includes information on issues such as what to expect, disclosure of ASD diagnosis, further resources, information on The Disability Standards for Education (2005) and the the Disability Discrimination Act (1992)**.**

http://www.latrobe.edu.au/otarc/info/support/students/transition-and-orientation

- Exploring the Possibilities: Post School Options for Young People with a Disability

A useful guide produced by DHS, in conjunction with DEECD and the Department of Innovation, Industry and Regional Development and the Victorian Advocacy League for Individuals with Disability Inc. (VALID).

http://www.dhs.vic.gov.au/__data/assets/pdf_file/0006/594645/exploring-possibilities-young-people-disability-2009-v1.pdf

- Futures for Young Adults

Futures for Young Adults (FFYA) is a Victorian government program that provides information, advice and support for up to three years to young people with a disability to help them make a successful transition from school to further education and employment. The type of support provided includes advice and guidance regarding the availability of post school options and referral to appropriate post school programmes, and the provision of funding to specialist disability services. FFYA can provide funded support for disability specific services for young people for whom generic community services are not able to meet their needs.

http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/reports-publications/futures-for-young-adults-2011-school-leavers-information-sheet

- Disability Liaison Units

Disability Liaison Officers (DLOs) are employed at each TAFE Institute in Victoria and University and may be able to provide the following:

- support for assessment requirements (additional time, scribe, reader)
- academic Support Workers (note takers, interpreters, readers)
- access to adaptive technology (voice activated software)
- alternative format course materials (Braille, disk)
- liaison with lecturers / teachers; physical access to facilities
- referral to other support services (counselling, health, housing, financial aid)
- enrolment and campus orientation

Work Education Units and Disability Liaison Units within TAFE Institutes operate under different structures and funding arrangements.

- Preparing for Higher Education: A Victorian guide for students with a disability

A booklet funded by the Australian Government under the National Disability Coordination Officer Program (2012).

http://ndco.wodongatafe.edu.au/Data/Sites/1/1710_ndco_preparingforuniversitybooklet_190912_web.pdf

- Preparing for TAFE: A guide for Students with a Disability in Victoria (2010).

A booklet funded by the Australian Government under the National Disability Coordination Officer Program

http://ndco.wodongatafe.edu.au/Data/Sites/1/0699_ndco_disabilityguidebook_191109web.pdf

- Special Entry Access Scheme (SEAS)

The Special Entry Access Scheme (SEAS) through the Victorian Tertiary Admissions Centre (VTAC) for applicants who have experienced educational disadvantage. SEAS does not change a students educational results or qualifications. It enables course selection officers to recognise that results or educational progress may have been affected by circumstances in the SEAS application, and to consider the effect of those disadvantages. Having a SEAS application does not guarantee an offer at a tertiary institution. Category 5 is for applicants who have experienced educational disadvantage as a result of a disability or medical condition.

http://www.vtac.edu.au/who/seas.html

## 2. Apprenticeship or traineeships

An apprenticeship or traineeship is a training contract between an employer and an employee in which the apprentice or trainee learns the skills needed for an occupation or trade. An apprenticeship or traineeship can be full-time or part-time basis and can be used as a valuable stepping stone to start a career in an industry for anyone of working age.

An apprentice or trainee can learn valuable, nationally recognised job skills, get paid while learning and combine formal training from a TAFE or training provider with workplace-based training

Students who are still at secondary school who want to complete VCE or VCA can complete a school-based apprenticeship or traineeship where time is spent at school, with the employer, and and also doing training with a TAFE or training provider.

- Apprenticeship Field Officers ph. 1300 722 603

Apprenticeship Field Officers support apprentices, trainees and employers. Apprenticeship Field Officers are responsible for giving regulatory advice and support to apprentices and trainees and their employers, including:

- investigating disputes between apprentices or trainees and employers
- supporting apprentices or trainees who are victims of workplace violence and harassment
- counselling and offering advice to apprentices, trainees and employers on training and other matters.

Apprenticeship Field Officers are also authorised officers with certain powers available to them under the *Education and Training Reform Act 2006* to help make sure that employer, apprentice and trainee obligations under a training contract are being met.

http://www.education.vic.gov.au/training/learners/apprentices/Pages/default.aspx

- Apprenticeship Support Officers ph. 1300 722 603

Apprenticeship Support Officers give support and guidance to all apprentices, aged 15 to 24, in the first year of their apprenticeship. Apprenticeship Support Officers offer advice and assistance on personal and workplace issues and work with Registered Training Organisations, Australian Apprenticeship Centres and other service providers to deliver an integrated apprenticeship support service. The Apprenticeship Support Officer Program aims to increase the rates of apprenticeship completion by providing targeted support to apprentices in the early stages of their apprenticeship.

http://www.education.vic.gov.au/training/learners/apprentices/Pages/default.aspx

- A Guide to Apprenticeships and Traineeships: Apprenticeships and traineeships in Victoria (DEECD, 2011)

http://www.education.vic.gov.au/Documents/training/learners/apprentices/guideapprtrain.pdf

## Employment

The transition from school or tertiary education to employment presents challenges for most young adults, however the challenges are likely to be more significant and particularly stressful for individuals with an ASD. There is evidence that many adults with an ASD remain without paid full-time employment (Howlin, 2003). Yet people with an ASD may thrive in a supportive, structured and well-organised workplace environment and have a range of strengths such as an eye for detail, reliability and application of routine tasks that are advantageous to an employer. However, the individuals' ongoing difficulties with impaired communication, social interaction and restricted and repetitive behaviours can be the cause of ongoing difficulties. Difficulties with understanding social rules, resistance to change, problems working independently, the development of inappropriate work patterns and personal self-care can all create employment difficulties. Adults with an ASD may also be vulnerable to bullying or mistreatment in the workplace. Having an ASD, particularly adults with HFA and Asperger's, can lead to misunderstandings in the workplace by those unaware of their colleague's diagnosis.

The problems encountered in finding and keeping a job often arise from the lack of available information, advice and practical support that is ASD specific. Mawhood and Howlin (1999) also commented that the investment in educating young people successfully to the end of secondary school and beyond is lost when the skills that young adults acquire are not able to be transferred to the workplace. Some researchers suggest that even for those generally regarded as most capable, that many individuals live lives of isolation and dependence, with few opportunities to improve their quality of life (Mawhood and Howlin, 1999, Gerhardt, 2007).

Gerhardt, (2007) states:

> "This outcome, however, should be seen more as system failure and evidence of the fact that there is a "disconnect" between what research indicates is possible for adult learners with ASDs and the outcomes most commonly realized. As such, there is critical need to revisit the ways in which such learners are prepared for adult life beyond the classroom, in the community, and on the job" (p. 26).

Howlin (2003) provides some valuable strategies on supporting adults with an ASD in employment including making the job requirements explicit, providing adequate supervision and management structure, providing clear feedback, making the 'rules' of behaviour explicit, managing obsessions and resistance to change, and providing personal support. Howlin also highlights the importance of ongoing involvement from a multidisciplinary team of professionals such as a psychologist, social worker or psychiatrist who know the individual well, to support their employment opportunities and assist in avoiding problems from arising.

- Futures for Young Adults

Futures for Young Adults (FFYA) is a Victorian government program that provides information, advice and support for up to three years to young people with a disability, to help them make a successful transition from school to further education and employment. The type of support provided may include advice and guidance regarding the availability of post school options and referral to appropriate post school programs and the provision of funding to specialist disability services. FFYA can provide funded support for disability specific services for young people for whom generic community services are not able to meet their needs.

http://www.education.vic.gov.au/aboutschool/careers/community.htm#1

- Youth Employment Scheme (YES)

The Youth Employment Scheme (YES) scheme provides traineeship opportunities within the Victorian Government for young people aged between 15 and 24. The aims of the scheme is to increase the participation of people in their communities and in the workforce, assist young people to gain paid work experience, training and qualifications that lead to sustainable employment and assist communities to meet future skill and employment needs

Applicants must be aged between 15 and 24 (as at the start of the traineeship), currently unemployed or not working more than 15 hours per week, not currently engaged in tertiary education, available for work and without a university qualification.

http://www.dbi.vic.gov.au/employment-with-us/employment-programs/youth-employment-scheme

- Disability Employment Services

The Disability Employment Services (DES )are a national network of community and private organisations dedicated to helping people with disability find work and keep a job in the open labour market. Under Disability Employment Services, all eligible job seekers with disability, injury or health condition are able to receive assistance from an employment service provider to prepare for, find and keep a job. Disability Employment Services include two programs, the Disability Management Service and the Employment Support Service.

The Disability Management Service provides assistance to people with disability, injury or health condition who need the assistance of Disability Employment Services and who might need irregular or occasional support to keep a job.

The Employment Support Service provides assistance to people with permanent disability and who require regular, ongoing support to keep a job.

http://jobaccess.gov.au/Services/A-Z_list/Pages/DisabilityEmploymentServices.aspx

- Alpha Autism

Alpha Autism specialises in the provisions of day service programs which are client focused and based on evaluated techniques aimed at assisting adults with an ASD in their transition from school to independence, employment opportunities and social inclusion. Alpha’s employment services address the needs of employers and clients, ensuring successful matches are made for sustained employment outcomes and community lifestyles.

Funding for many of Alpha Autism’s services is provided by the Department of Human Services (Victoria) Individual Support Packages and through Department of Workplace Training for the provision of Employment Services. In addition to this, clients and their families/carers can access fee-for-service support as needed.

http://www.alpha-autism.org.au/

- Making the transition to an apprenticeship or traineeship (2012)

A booklet funded by the Australian Government under the National Disability Coordination Officer Program. Easing the Transition into an Apprenticeship or Traineeship for people with a disability.

http://www.ndcoceagroup.com.au/uploads/NDCO-Files/TransitionResources/NDCO%20Transition%20to%20Apprenticeship%20-%20June%202012.doc

- Disability Employment Services

Disability Employment Services (DES) were formerly known as Disability Employment Networks and provide eligible jobseekers with disability, injury or health condition, access to individually tailored employment services suited to their needs.

http://jobaccess.gov.au/Services/A-Z_list/Pages/DisabilityEmploymentServices.aspx

To find the nearest DES provider:
http://jobsearch.gov.au/provider/ProviderLocation.aspx?maplevel=2&ProviderType=DES&regionkey=VIC

## Community participation and recreation

There are many opportunities for participation in community activities for individuals with an ASD. There are universal activities such as fitness clubs, pools, sporting groups, libraries, exhibitions and social clubs that are available for all Victorians. There are also a wide range of specific groups and activities for adults with a disability, or for those with an ASD.

Physical exercise and leisure activities for individuals with an ASD are attracting a growing body of research interest. The National Standards Report (2009) cited four peer-reviewed studies on the use of physical exercise for individuals with an ASD as a means of reducing problem behaviours or increasing appropriate behaviour, and rated physical exercise programmes as an emerging treatment. More recently, Lang et al. (2010) conducted a systematic review of physical exercise interventions for individuals with ASDs and reported a decrease in stereotypy, aggression, and off-task behaviour, and an increase in on-task behaviour in response to physical activities such as jogging, weight training, swimming and bike riding. Improved physical and mental health and a positive effect on level of stress and quality of life in response to physical exercise have also been reported (Garcia-Villamisar & Dattilo, 2010; Garcia-Villamisar & Dattilo, 2011; Lang et al., 2010). Furthermore, Lang et al. (2010) suggested that deficits in motor abilities found in individuals with an ASD may be exacerbated by reduced opportunities to engage in physical activity Leisure pursuits for individuals with an ASD are found to be more likely solitary rather than community based (Jennes-Coussens, Magill-Evans & Koning, 2006).

- Access for all Abilities

Access for All Abilities is a Victorian Government initiative coordinated by Sport and Recreation Victoria. The program supports and develops inclusive sport and recreation opportunities for people with a disability throughout Victoria. Access for All Abilities providers work at a community level to develop inclusive sport and recreation opportunities for people of all abilities. Access for All Abilities providers work in all Victorian local council areas.

http://www.dpcd.vic.gov.au/sport/inclusive-sport/Access-For-All-Abilities

- Alpha Outbound

Alpha Outbound provides its members with an opportunity to participate in social activities assisted by experienced support workers. This allows families and carers to access respite services.

http://www.alphaautism.org.au/respite-and-recreation/

- Alpha social club

Alpha Autism supports a Social Club and Girls Group specifically for adults living with an ASD. The clubs are organised by a committee of members who plan events for a six month period. Alpha assists in the co-ordination and planning of the social calendar but does not provide any staff or facilitators for the actual events. Events include exhibitions, shopping, eating out, sports and road trips. Members pay their own costs and need to arrange their own transport

http://www.alphaautism.org.au/social-club

- Asperger Syndrome Support Network (ASSN)

Asperger Syndrome Support Network (Vic) Inc. is a volunteer group of parents, carers, partners, professionals and individuals with Asperger's, who aim to provide support and information. One of their initiatives is a monthly meeting and social events for adults with Asperger Syndrome. ASSN has a useful website that contains information on leisure and social skills groups throughout Melbourne.

http://www.assnvic.org.au/

## Independent living and accommodation

- Accommodation support options through DHS

1. Support to live in own home, or the family home through an Individual Support Package http://www.dhs.vic.gov.au/for-individuals/disability/individual-support-packages

2. Shared and supported accommodation (formerly known as a Community Residential Unit) is a group home for individuals with disabilities, including an ASD. Shared Supported Accommodation is for people who require rostered support and is targeted to people with a disability with the highest support needs. These can vary in their level of support. Individuals of similar support needs share a house that typically accommodates 4-6 residents.

3. Support for younger people at risk of admission to residential aged care (My Future My Choice)

http://www.dhs.vic.gov.au/for-individuals/disability/accommodation

- Statewide Autistic Services

Statewide Autistic Services offer a range of services to people with ASDs their families, and the community including adult day services and full-time accommodation

http://www.sasi.org.au/index.php

## The family

Hare et al. (2004) investigated the social and psychological needs of parents caring for a young adult with an ASD (aged 16 years and older) and reported a strong association between the unmet needs of parents and their emotional distress. They reported that parents no longer attended support groups that they had previously attended when their child was young. Parents were found to have a reduced capacity to care for their family member with an ASD, and a reduced ability to negotiate effectively with the service system. They also reported that parents requested more autism specific interventions and services for adults with ASDs, and suggested that parent support should be reassessed to take account of changing family and developmental needs over time.

At times parents may require respite and a break from the challenging demands of caring for their child with an ASD who is now an adult, but may still be living at home. Parents may need time out to look after their own needs and to care for their own physical and mental health to enable them to provide optimum care for their adult child. Respite support can include community participation, in-home support or out of home support.

- Respite Victoria

Respite Victoria has been established as part of the Victorian Department of Human Service's initiatives to improve access to information about respite for carers and people with a disability in Victoria. Respite Victoria has links to the 8 regional disability respite websites in Victoria. Each regional website links you to the Respite Service Search (local and state-wide), and has specific local information, news and events.

http://www.respitevictoria.org.au/what-respite

- Carers Victoria

Carers Victoria work closely with government and other support organisations to improve the lives of caring families throughout Victoria.

http://www.carersvictoria.org.au/

## Financial Support

- The Carer Allowance (Centrelink)

Centrelink Carer Allowance payments cease when a child turns 16. A new claim for Carer allowance (adult) needs to be submitted as the payment change does not happen automatically. Centrelink provides a range of payments for people with a disability over the age of 16, however not all individuals with an ASD will be eligible. Contact should be made with a Centrelink Customer service Officer prior to the young person's 16th birthday.

http://ww.centrelink.gov.au/internet/internet.nsf/forms/ci002.htm

- Disability Support Pension (Centrelink)

Disability Support Pension is a payment for individuals whose physical, intellectual or psychiatric impairment prevents them from working of retaining work for two years or more.

http://ww.centrelink.gov.au/internet/internet.nsf/forms/ci002.htm

- Chronic Disease Management Plan (Medicare)

The Chronic Disease Management Plan provides five sessions with an allied health professional per calendar year and funding for dental treatment. The plan can be written by a GP.

http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-chronicdiseasemanagement

- Mental Health Care Plan (Medicare)

Medicare rebate through a Mental Health Care Plan provides six sessions with an allied health professional. An additional four session may also be available in exceptional circumstances. Ten group sessions with an allied health professional are also available. This is available for the individual with an ASD, parents, siblings and carers who may need help with their mental health and wellbeing.

http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-b-better

## Advocacy

- National Disability Advocacy Program

The National Disability Advocacy Program (NDAP) provides individuals with a disability access to advocacy to promote, protect and ensure their full and equal enjoyment of all human rights and enabling community participation.

http://www.fahcsia.gov.au/sa/disability/progserv/providers/NationalDisabilityAdvocacyProgram/Pages/NationalDisabilityAdvocacyProgram.aspx

- Disability Advocacy Resource Unit (DARU)

DARU is a statewide service established to resource the disability advocacy sector in Victoria. The resources that DARU provides aims to support the Disability Advocacy sector and Disability Advocates through disseminating relevant and up to date information, organising forums around the state so that there is a coordinated approach to issues of concern, providing professional development opportunities and undertaking capacity building projects on behalf of the sector

http://www.daru.org.au/

- Action on Disability in Ethnic Communities (ADEC)

The role of the Advocacy Program is to work in partnership with clients to achieve goals that meet individual needs and to ensure equity of access and participation in the community. Clients may come from any non-English background, any age, gender, or religion.

http://www.adec.org.au/advocacy.html

- National Autistic Society (NAS)

In consultation with adults who have autism and parents, the NAS has developed an ‘Alert Card’, designed to tell people about the condition and asking them to show respect and tolerance. The Alert Card is available in many community languages. Note: the contact details on the card are for UK services.

http://www.autism.org.uk/

- Victorian Advocacy League for Individuals with Disability Inc. (VALID) ph. 9416 4003

Advocacy support for adults with an intellectual disability. Professional information, education & support

www.valid.org.au

## Professional information, education and support

There is a relatively limited range of professional education in Victoria on working with adults with an ASD and their families. However, several agencies provide training, communities of practice and important resources.

- Mindful: Centre for Training and Research in Developmental Health

A training program in assessment, diagnosis and treatment for Paediatric fellows, Psychiatric registrars and mental health clinicians has been funded by the Department of Health and designed and delivered by Mindful: Centre for Training and Research in Developmental Health, University of Melbourne. Regular training is provided on the fundamental of ASDs assessment and diagnosis and is enhanced by follow-up seminars on assessment and treatment for adolescents and young adults, and workshops on specific ASD assessment instruments (e.g. ADOS).

http://www.mindful.org.au/Home.aspx

- Amaze (Autism Victoria)workshops, courses and information

Amaze Knowledge delivers a range of structured and personalized education courses for services and organizations directly involved in supporting individuals and families with an ASD. They also have a certified training course and arrange speakers for conferences and special events.

Customer Focus: to enable staff to assist individuals with a disability where these individuals are customers of the organization. This helps your staff recognise the characteristics of an individual with a disability and learn how to assist them respectfully and with dignity.

Staff and Management Focus: to improve staff and management awareness and support of diversity in the workplace. This improves inclusion for diverse staff members and helps to provide a positive workplace where differences are understood and respected.

http://www.amaze.org.au/discover/how-we-can-help-you/learning-education/

- Victorian Dual Disability Service (VDDS)

VDDS provides training to clinicians working in area mental health services in Victoria. Training sessions include; assessment, challenging behaviours, ASDs and management. VDDDS also delivers a range of lectures, tutorials, workshops and information sessions including contribution to the bachelor of applied science at RMIT.

http://www.svhm.org.au/services/VictorianDualDisabilityService/Pages/Training.aspx

- Communities of Practice

Case Consultation Practitioners are employed by DHS in each region across Victoria. They are responsible for providing secondary consultation to disability case managers and developing or building on existing local networks to enhance linkages and pathways.
They have also created ‘communities of practice’ to provide a means of continual learning and development for disability services staff.  Case consultant practitioners are based at various organisations across Victoria.

| REGION | ORGANISATION | EMAIL |
|---|---|---|
| **North/West** | Autism Vic. | www.amaze.org.au/learning |
| **South** | Windermere | www.windermere.org.au |
| **East** | Autism Vic. | www.amaze.org.au/learning |
| **Hume** | Mansfield Autism Statewide Services | www.autismmansfield.org.au |
| **Loddon-Mallee** | Community Living & Respite Services Inc. | www.clrasd.org.au |
| **Gippsland** | SCOPE | https://sites.google.com/site/autismgippsland/ |
| **Barwon S-W** | Gateways<br>MPOWER | www.gateways.com.au<br>www.mpower.org.au |

- Alpha Autism

Alpha Autism Consultancy Services assist workplaces with developing tailored training solutions.

http://www.alpha-autism.org.au/

- National Autistic Society (NAS)

The NAS has a comprehensive website that includes a section for adults with an ASD. Useful resources include printable tip sheets on topics such as making friends and telling people that you have an ASD.

http://www.autism.org.uk/

- Disability Certificate IV training

This qualification is part of the Community Services Training Package. It provides the skills and knowledge required for working in training resource centres, day respite centres, open employment services, residential group homes, other community settings and clients' homes. Workers in this area provide training and support to people with disabilities to enhance their levels of independence, self reliance and community participation

http://www.tafe.vic.gov.au/tafecourses/search/Courses/Detail.asp?ID=41376

# Other considerations (Adulthood)

## Outcome

One of the earliest studies of the trajectory of individuals with autism was Kanner's (1973) follow-up study of ninety-six children reassessed in their twenties and thirties. Since that time, there have been few systematic outcome studies that have reported on the progress of individuals with an ASD as they move through adolescence and into adulthood. Most studies have involved small cohorts, imprecise diagnostic criteria and/or poor quality data on intellectual functioning (Howlin, 2005).

Gillberg (1991) indicated that only a small number of individuals with autism lead self-supporting lives, with approximately two-thirds remaining dependent on others throughout life. Nordin and Gillberg (1998) in their review of outcome studies reported that "the majority of children with autism show deviance and socially or psychiatrically handicapping conditions throughout life" and that "only a small proportion of those with classical childhood autism lead independent adult lives". They also suggested that the individual's level of ID and other comorbid conditions (medical syndromes and neuropsychiatric disorders, including epilepsy) are important in predicting outcome (Nordin & Gillberg, 1998).

Autism is not a static disorder, but there is "a pattern of improvement from childhood to adolescence and adulthood" and for some individuals, some abatement of symptoms over time (Seltzer et al., 2003, p. 577). Seltzer, Shattuck Abbeduto & Greenberg (2004) in their review of prospective, retrospective and cross-sectional studies reported modest degrees of symptom abatement and improvement in skills, with approximately 15% having more favourable adult outcomes, but the majority of individuals with autism continuing to have significant degrees of symptomatology and dependency on others. Howlin et al. (2004) reported on the outcome for more able individuals and found that although people with HFA or Asperger's disorder may succeed, these achievements are not easily come by. Families provided support in helping the individual to find employment and accommodation rather than the few specialist services. Howlin concluded: "If those who are high functioning are to be given the opportunity to make the most of the skills they undoubtedly possess, much more is required in terms of appropriate educational facilities, help with supported living and accommodation and the development of wider social support networks…clinical expertise needs to be enhanced…to improve recognition and treatment of emotional or psychiatric disturbance" (p. 79).

Howlin et al. (2004) found that the most significant factor determining outcome appears to be intellectual functioning, but that even for those individuals with an IQ over 70, the degree of ritualistic and stereotyped behaviours may "swamp the effects of a relatively high IQ" (Howlin et al., 2004, p. 226). The other factor that has been consistently associated with outcome has been early language development, with children who have not developed functional speech by five-six years of age having poorer outcome (Howlin, 2005). Shattuck et al. (2007) studied 241 individuals with an ASD over 4½ years. They found that although symptoms remained stable in many, those with an ID had more autism symptoms and maladaptive behaviours than those without ID and had improved less over time. More recently, Farley et al. (2009) found adaptive behaviour to be more highly associated with outcome than cognitive factors. Darrou et al. (2010) concurred with others in their study on the outcome profiles of young children with autism, that symptom severity and speech development were significant risk factors, but they also found outcome was not linked to gender, socioeconomic status, medical condition, or hours of intervention. Several researchers have indicated that the individual's ability to function independently may also depend on the level of support offered by families, employment and social services (Lord & Venter, 1992; Mawhood & Howlin, 1999).

## Health

ASDs are not degenerative disorders. However, associated medical conditions such as epilepsy or accidents related to significant ID have been reported to be related to early deaths (Shea & Mesibov, 2005). Whilst some studies have reported a significantly higher death rate for individuals with PDDs than the expected mortality rate (Mouridsen, Bronnum-Hansen, Rich, & Isager, 2008; Shavelle et al., 2001) the vast majority of individuals with and ASD live at least through middle age and beyond. Some reports suggest that individuals with autism and ID have fewer of the risk factors such as smoking and alcohol consumption that are associated with typical adult lifestyles (Shavelle et al., 2001).

There is a known association between autism and epilepsy with prevalence rates of epilepsy in those with autism varying from 5% - 40% compared to the general population of .5% - 1% (Amiet et al., 2008). The risk for epilepsy in autism is higher for girls and for individuals who also have an intellectual disability (Amiet, et al, 2008) and also for those who have had a traumatic birth (Larson et al., 2005). Peak periods of seizure onset are reported to be in early childhood and adolescence (Tuchman & Rapin, 2002).

- The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health (CDDH) strives to improve the health and healthcare of people with a disability by enhancing the capacity of mainstream health services through educational activities, research projects, clinical services and advocacy initiatives. CDDH run sessions for professionals involved in the healthcare of people with developmental disabilities. They conduct consultancy and research clinics, as well as clinical services for people with developmental disability.

http://www.cddh.monash.org/

- Annual Health Assessment (Medicare)

All patients with an intellectual disability are eligible for an annual health assessment (one per patient in any 12 month period). This is an evidence based service funded by the Medicare Benefits Schedule (MBS), which recognises that the health needs of patients with an ID are often unrecognised.

The annual health assessment provides an opportunity for the GP to identify and manage any health problems as well as to undertake disease prevention. Patients (or their carers) might request a health assessment or they may be identified by the practice when they present in relation to another matter or through practice audit.

Prior to attending for a health assessment, the patient’s carer will often provide the GP with a Comprehensive Health Assessment Program (CHAP). The CHAP is a health assessment tool which provides information about the patient’s past history and guides the GP through the health assessment by prompting the GP to be aware of commonly missed, difficult to manage or syndrome specific health conditions for patients with an intellectual disability. It is the GPs decision whether to use CHAP or not.

Completion of the annual health review usually includes review of medications, preventive health measures, detection of co-morbidity, and identification of risk factors and management of active health needs. Findings may prompt further investigation or referral, or development of a GP Management Plan/Team Care Arrangements.

http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-qandaintelldisability

## Mental Health

Individuals with and ID are at an increased risk of a co-occurring mental illness compared to the general population and can be particularly difficult to detect due to communication difficulties and lack of guidelines on the diagnosis and treatment for this group of people with a dual disability (Thomas, Corkery-Lavender, Daffern & Sullivan, 2010).

Individuals with autism have been found to be at risk of developing a new psychiatric disorder by adult life (Hutton, Goode, Murphy, LeCouteur & Rutter; 2008). All types of psychiatric disorders occur in individuals with an ASD (Ghaziuddin, 2005; Hutton et al., 2008) and they present with more psychiatric symptoms or disorders than the general population (Bradley et al., 2004; Bradley et al., 2007; Gadow et al., 2004; Gillberg & Billstedt, 2000; Leyfer et al., 2006; Simonoff et al., 2008; Tonge & Einfeld, 2003). Psychiatric disorders can also be multiple in those with an ASD (Simonoff et al., 2008). These primarily include anxiety disorders (Fombonne, 1992; Gillot, Furniss & Walter, 2001; Nick, Szatmari, Bryson, Streiner & Wilson, 2000; Simonoff et al., 2008) depression and other mood disorders (Bradley et al., 2004; Brereton et al., 2006; Lainhart & Folstein, 1994; Ghaziuddin, Ghaziuddin & Greden, 2002; Tonge & Einfeld, 2003).

Accurate diagnosis of comorbid psychiatric conditions in young people with an ASD is critical as the comorbid disorder may cause significant impairment and additional burden of illness on the individual and their family, and requires specific treatment (Leyfer et al., 2006). While comorbid psychiatric symptoms in those with an ASD is now well described in the literature, infrequent identification and diagnosis may be due to diagnostic overshadowing in which the psychiatric symptoms are attributed to the ASD or ID (Simonoff et al., 2008). The impact of comorbid mental health problems on the long-term adjustment, wellbeing and outcome for individuals with an ASD is still unclear. There is evidence of increased genetic vulnerability to a range of mental health problems, such as the association with familial depression (Bolton, Pickles, Murphy & Rutter, 1998; Piven & Palmer, 1999), bipolar disorder (DeLong & Dwyer, 1988) and ADHD (Goldstein & Schwebach, 2004; Reierson, Constantino, Volk & Todd, 2007).

The Victorian Government’s Office of the Senior Practitioner released a report in 2010 on disability, mental health and medication with the aim of understanding current practice on restricted interventions and compulsory treatment for individuals with a dual disability (Thomas, Corkery-Lavender, Daffern & Sullivan, 2010). The report indicated that medication is increasingly common in the treatment of behaviours of concern for individuals with a dual disability.

- The Developmental Behaviour Checklist- Adult (DBC-A) is a 107 item instrument for the assessment of behavioural and emotional problems of adults with developmental and intellectual disabilities and is completed by family members or paid carers who know the person well. It can be used in clinical practice in assessments and monitoring interventions, and in research studies. The DBC-A has been translated into other languages: Dutch, Finnish and French.

http://www.med.monash.edu.au/spppm/research/devpsych/dbc.html

## Anxiety disorders

Anxiety disorders differ from fears and worries, which are common in individuals with an ASD, in the level of severity, associated distress and life interference. Studies report high rates of anxiety disorders in individuals with an ASD (Fombonne, 1992; Gillot et al., 2001; Nick et al., 2000; Simonoff et. al., 2008). In addition to generalized anxiety disorder, individuals with an ASD can also develop distinct anxiety disorders such as obsessive compulsive disorder and post traumatic stress disorder (Ghaziuddin, 2005). Symptoms of anxiety, (e.g. fears, resistance to change, panic, phobias, tenseness, shyness, irritability and somatic symptoms) cause distress and impairment for the individual, but also have the potential to disrupt education, further impair social interaction and create management problems and stress for the parents and carers. Individuals with symptoms of anxiety may respond to cognitive and behavioural treatment approaches and also to pharmacological treatments (Tonge & Einfeld, 2003).

## Depression & other mood disorders

Mood disorders, including depression, are the most common psychiatric disorder occurring in the general population (Ghaziuddin, 2005), characterised by depressed mood, irritability, sleep and appetite disturbance, obsessional thoughts, lethargy and a loss of enjoyment or pleasure in normally enjoyable activities. Individuals with an ASD are at increased risk of suffering depression and mood disturbance (Bradley et al., 2004; Brereton et al., 2006; Lainhart & Folstein, 1994; Ghaziuddin, Ghaziuddin & Greden, 2002; Sterling, Dawson, Estes & Greenson, 2008; Tonge & Einfeld, 2003) probably due to both biological and environmental factors (Brereton et al., 2006).

Whilst prevalence is not known, studies suggest that it is the most common psychiatric disorder seen in individuals with an ASD, but can be difficult to diagnose in those with severe cognitive and communication impairment (Ghaziuddin, 2005). Those individuals with an ASD suffering from depression often display an exacerbation of symptoms, such as social withdrawal and an increase in obsessive compulsive behaviours. They may also display a change in character of their obsessional interests and activities, irritability, sadness, aggression or a regression in skills (Ghaziuddin, 2005). Children with autism are more likely to have a family history of depression (Ghaziuddin & Greden, 1998). In particular, mothers of children with autism are more likely to suffer from depression than mothers of children with an I.D. without autism and also mothers of typically developing children (Bristol, Gallagher & Holt, 1993; Olsson & Hwang, 2001; Piven & Palmer, 1999; Wolf, Noh, Fisman & Speechley, 1989; Yirmiya & Shaked, 2005). Individuals with an ASD may respond to psychological treatments such as cognitive therapy, relaxation training, and pleasant events scheduling, as well as pharmacological treatment for severe or persistent depressive symptoms.

- ➢ Victorian Dual Disability Service (VDDS)

The Victorian Dual Disability Service is a state-wide mental health service for people with an intellectual disability. In Victoria the term Dual Disability is used to describe people with an intellectual disability who also have a mental health problem. VDDS provides clinical support and training and has some valuable publications on a range of issues. Clinical support includes the provision of advice to anyone about the mental health of people with an ID in relation to:

- Assessment for an ASD
- Presentation of mental disorders
- Mental health assessment
- Treatment for a mental disorder
- Management of mental and behavioural disorders
- Services available in Victoria and how to access these services

http://www.svhm.org.au/services/VictorianDualDisabilityService/Pages/VictorianDualDisabilityService.aspx

- Adult specialist mental health services (16-64 years)

Adult specialist mental health services are aimed primarily at people with serious mental illness or mental disorder who have associated significant levels of disturbance and psychosocial disability due to their illness or disorder. Commonly these will be people with a diagnosis of a major mental illness, such as schizophrenia or bipolar disorder, but will also include some people with other conditions such as severe personality disorder, severe anxiety disorder, or those who present in situational crisis that may lead to self-harm or inappropriate behaviour towards others. The distinguishing factor is the level of severity of the disturbance and impairment.

http://www.health.vic.gov.au/mentalhealth/services/adult/

- The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health (CDDH) strives to improve the health and healthcare of people with a disability by enhancing the capacity of mainstream health services through educational activities, research projects, clinical services and advocacy initiatives. CDDH run sessions for professionals involved in the healthcare of people with developmental disabilities. They conduct consultancy and research clinics, as well as clinical services for people with developmental disability.

http://www.cddh.monash.org/

- Autism Spectrum Australia (Aspect)

Autism Spectrum Australia (Aspect) provides a Positive Behaviour Support Program for children and young people (aged 6-25 years) with an ASD. The programme offers three levels of support.

1. Parents can access free Positive Behaviour workshops designed to support and assist families, carers and others to develop a greater understanding of the individual with ASD and the impact that this has upon learning, behaviour and development, and to design and implement an individualised positive behaviour support plan based upon an identified behaviour of concern.
2. Families of clients who require support at a more intensive level can participate in these Positive Behaviour Workshops, but, in addition, will be able to apply to receive individualised support to define specific goals and to design and implement a detailed behaviour support plan in the home and in other settings (including schools). Additional training and support will be provided to local services.
3. The highest intensity of support is longer term and designed to address issues with people who have more complex needs and enduring challenges. Clients requiring this level of support may be at significant risk of family breakdown or loss of school placement.

http://www.autismspectrum.org.au

## Sexuality & relationships

Sexuality is an integral part of human development and includes gender, sexual identity, reproduction and sexual orientation (Jones & Chivers, 2011). Whilst there is a limited literature on issues of sexuality and relationships of people with ASDs, there is no doubt that it is an important issue. The broader literature on people with developmental disabilities indicates that the information and support people with a disability have influences their sexual health, their ability to make informed decisions, develop relationships and remain safe. Furthermore, lack of support may lead to exploitation, vulnerability to abuse, poor health and contact with the criminal justice system (Jones & Chivers, 2011).

Several studies have found that the majority of adolescents and young adults with an ASD express sexual interest and have a variety of sexual behaviours (Hellemans et al., 2007; Hellemans et al., 2010; Konstantareas & Lunsky, 1997). Adolescents with an ASD usually have to learn about social skills and relationships without the opportunity of peer group discussion and support available to typically developing adolescents (Howlin, 2005). Furthermore, individuals with an ASD have been found to show more difficulties with the external changes of the body during puberty (Hellemans et al., 2010). The complexity of developing and maintaining intimate and sexual relationships can be perplexing for adults with an ASD. Difficulties with understanding social relationships and interactions, problems with developing empathy for others' and intense interests, non-functional routines and rituals can all lead to misunderstanding and confusion.

Jones and Chivers (2011) identified a number of elements to sexual education for young people with learning difficulties. Many of these are also pertinent to those with an ASD and include:

- information about the changing bodies and integrity of their body
- rules about social sexual behaviour
- a safe environment
- support in developing positive sexuality
- skills in developing and maintaining friendships
- opportunities to develop intimate relationships
- opportunities to take risks to enable independence
- access to health services
- advocacy (p 195).

- The Centre for Developmental Disability Health (CDDH)

The Centre for Developmental Disability Health provides a range of supports and services related to children, adolescents and adults with a developmental disability and sexuality. This includes educational counselling to individuals and couples with developmental disability, sexual knowledge assessments and identification of human relations needs, education sessions for people with developmental disability, staff, parents/carers, professional and community organisations, telephone consultation, tertiary consultations. They also provide human relations educational materials.

http://www.cddh.monash.org/sexuality-disability.html

- Amaze (Autism Victoria) factsheet: Romantic Relationships and ASD

http://www.amaze.org.au/uploads/2011/08/Fact-Sheet-Romantic-Relationships-ASD-Aug-11.pdf

## Guardianship and legal concerns

Like all young adults who turn 18 years of age, individuals with an ASD are legally entitled to make decisions for themselves. This is the case whether they have an ID or not. This can be surprising and confusing for parents who have cared for their child and been the primary decision maker for many years. However, there are times when parents or other family members are aware that an adult with an ASD may require additional help with making informed decisions about medical or financial issues, or other matters of daily life. The Victorian Civil and Administrative Tribunal (VCAT), Office of the Public Advocate (OPA) and State Trustees can provide further information , support and services.

- Victorian Civil and Administrative Tribunal (VCAT)

VCAT is a Tribunal that makes decisions about a range of disputes. Applications may include applications for orders such as:

- appointing guardians to make decisions for a person, including accommodation
- appointing administrators to manage a person's financial and legal affairs
- revoking an attorney's appointment, or varying, suspending or making another order in relation to a financial enduring power of attorney under the *Instruments Act* 1958
- revoking or suspending an enduring power of attorney (medical treatment) under the *Medical Treatment Act* 1988
- consenting to a "special procedure". That is, a procedure intended or likely to cause infertility, termination of pregnancy or removal of tissue for transplanting.

VCAT also hears and determines applications under the *Disability Act* 2006 to:

- review decisions by the Secretary to the Department of Human Services to admit a person with an ID to a residential institution
- review decisions about "restrictive interventions" (the restraint or seclusion of a person with a disability)
- make orders about residential treatment facilities, including a resident’s treatment plans and leave of absence

- make orders about "security residents" (persons with an ID transferred from prison to another facility), including a security resident’s treatment plans and leave of absence
- make and review supervised treatment orders for persons with an ID if satisfied that, among other things, the person must be detained to prevent serious harm to another person

http://www.vcat.vic.gov.au

- ➢ Office of the Public Advocate (OPA)

The OPA is an independent statutory body that works to protect and promote the interests, rights and dignity of people with a disability. A range of services include:

- Advice and information about matters including powers of attorney, guardianship, VCAT applications and consent to medical and dental treatment

- Advocate/Guardian program for volunteers who are appointed by the public advocate to act as independent guardians for people with a disability

- Community visitors programme. Volunteers who visit accommodation facilities for people with a disability or mental illness

- Independent third person programme. Volunteers who assist people with an ID or mental illness during interviews or when making formal statements to police

- Education sessions on topics such as enduring powers of attorney and medical consent

http://www.publicadvocate.vic.gov.au/

- ➢ State Trustees

State Trustees is a state owned company that provides a range of services for people who can’t manage their own affairs because of their disability. They provide financial and legal assistance including will and executor services and the special disability trust.

http://www.statetrustees.com.au/about-us

## Criminal Justice

Although there is a limited research on ASDs and criminal justice, there appear to be some emerging trends. The majority of individuals with an ASD are law abiding and do not come into contact with the criminal justice system as a victim, witness, suspect or offender. However, individuals with developmental disabilities, including ASDs, are more likely than typically developing individuals to be the victims of crime and/or exploitation (National Research Council, 2001).

Some researchers have suggested that the core features of ASDs, including social naivety, a poor understanding of others' perspectives and restricted and repetitive interests and patterns of behaviour, may contribute to illegal behaviour in individuals with an ASD (Cheely et al, 2011; Mayes, 2003; Woodbury-Smith et al, 2005). It has also been suggested that high rates of comorbid psychiatric conditions in individuals with an ASD may also increase the risk for committing offences and being in contact with the law (Vermeiren et al, 2006). Others have suggested that the very literal and pedantic adherence to rules and the law of those with an ASD make it less likely they will engage in an offence (Howlin, 1997).

Haskins and Silva, (2006) suggested that deficits in theory of mind, intense narrow interests and poor interpersonal skills may heighten the risk for engaging in criminal behaviour in individuals with Asperger's Disorder. A study by Scragg and Shah (1994) found that criminality is associated more often with Asperger's disorder than Autism. Haskins and Silva, (2006) suggested that as forensic clinicians are becoming more familiar with the presentation of Asperger's disorder, individuals with Asperger's are over-represented in forensic criminal settings.

Once an individual with an ASD is in the criminal justice system, the nature of their difficulties may not be recognised or may be misunderstood. In these circumstances it is possible for miscarriages of justice to occur and it is therefore critical that legal experts are familiar with ASDs. Appropriate support needs to be in place in order that adults with an ASD are understood and appropriately represented.

Some studies also discuss the degree of criminal responsibility in people with ASDs. Because of deficits in empathy, there may be important repercussions when assessing remorse in criminal proceedings when the offender has Asperger's Disorder (Haskins & Silva, 2006). Barry-Walsh and Mullen, (2004) presented five case histories of a person with Asperger's disorder who had a history of offending. In each case, the offence was understandable in the context of the disorder and all were "surprised by the reactions their actions evoked in others and had difficulty understanding why they were now facing criminal charges" (p 105).

> "…it behoves us to draw to the courts' attention the obvious: that patients with Asperger's Disorder suffer from mental disorder and that their offending and subsequent disposition must be placed in this context. The core features of Asperger's Disorder and how they determine what the individual knows and understands of the world should form a basis for sophisticated assessment of the issues of disability and legal insanity" (Barry-Walsh and Mullen, 2004, p 106).

Howlin (2003) suggests that whilst approaches to intervention must be individualised, an emphasis must be placed on early intervention with an understanding that behaviours that appear innocuous in a young child take on a different perspective in an adult (e.g. hugging unfamiliar adults when greeting them). Howlin emphasises the need to establish consistent rules and provide appropriate social skills training.

- Autism: a guide for criminal justice professionals (National Autistic Society )

A practical guide for criminal justice professionals in the UK who may come into contact with an ASD as victims, witnesses, suspects or offenders. It is based on the experiences of people with an ASD and those who work with them, and contains real-life examples and personal accounts by professionals. Much of the guide is also useful in an Australian context.

http://www.autism.org.uk/working-with/criminal-justice/autism-a-guide-for-criminal-justice-professionals.aspx

## Cultural awareness

Culture is “the shared way of life including attitudes, beliefs, norms and values of people” (Powie, 2012, p. 63).There are inevitable stressors for people who are adapting to a new country, culture, social system and language. Families from culturally and linguistically diverse (CALD) backgrounds may experience stressors due to settlement issues, trauma, pre-post immigration experiences, unemployment, limited social support and poverty (Baasiri & Carroll, 2011). There may be additional cultural complexities to the adjustment and wellbeing of individuals with a disability, including those with an ASD, and their families. Cultural differences in family members’ responses to disability have been reported to influence levels of stress and long-term outcomes (Echemendia & Westerveld, 2006). Culturally awareness and sensitivity is important in the fields of disability and mental health. Baasir & Carroll (2011) stated that “Clinicians need to adjust the way they provide health and mental health services, using knowledge of the culturally mediated values, attitudes, and experiences that apply to a given case, and through effective communication skills, and a willingness to advocate on behalf of families” (p. 44).

- Action on Disability in Ethnic Communities (ADEC)

ADEC provides individual advocates assist individuals with a disability from a diverse background and/or their carers. Clients may come from any non-English background and may come from any age, gender, or religion.

http://www.adec.org.au/advocacy.html

- Cultural Diversity Plan for Victoria’s Specialist Mental Health Services (DoH)

The Cultural Diversity Plan for Victoria’s Specialist Mental Health Services provides a framework for improving the accessibility and responsiveness of mental health services to Victoria’s culturally and linguistically diverse communities. The Cultural Diversity Guide identifies a range of strategies to improve cultural responsiveness, recognising that no single strategy suits every program and agency and there are many different pathways to equitable, high quality service provision. It provides examples of good practice, as well as guidance on additional resources and supports to respond to diversity for programs and agencies.

http://www.health.vic.gov.au/diversity/cald.htm

- The Transcultural Mental Health Access Program (ADEC)

ADEC works with ethnic communities to raise awareness about mental health problems and ways to access mental health and carer services, assists mental health services with developing culturally responsive models and strategies of working with ethnic communities and works with community and ethno-specific organisations to raise their awareness of the impact of mental illness on ethnic communities and ways of assisting their clients to better access appropriate mental health services.

http://www.adec.org.au/index.php/services/mental-health

- Victorian Transcultural Psychiatry Unit

The Victorian Transcultural Psychiatry Unit (VTPU) is a state-wide unit which supports area mental health and psychiatric disability support services in working with CALD consumers and carers throughout Victoria.
http://www.vtpu.org.au/links/

MONASH UNIVERSITY

THE UNIVERSITY OF MELBOURNE

# JARGON BUSTER

| | |
|---|---|
| **AAC** | Alternative and Augmentative Communication |
| **ADHD** | Attention-Deficit Hyperactivity Disorder |
| **ADI-R** | Autism Diagnostic Interview- revised |
| **ADOS** | Autism Diagnostic Observation Schedule |
| **AMHS** | Adult Mental Health Services |
| **ASD** | Autism Spectrum Disorder |
| **APA** | American Psychiatric Association |
| **CALD** | Culturally and Linguistically Diverse |
| **CARS** | Childhood Autism Rating Scale |
| **CATT** | Crisis Assessment and Treatment Teams |
| **CRUs** | Community Residential Units |
| **DHS** | Department of Human Services (Victoria) |
| **DEECD** | Department of Education & Early Childhood Development (Victoria) |
| **DEEWR** | Department of Education, Employment & Workplace Relations (Commonwealth) |
| **DLOs** | Disability Liaison Officers |
| **DoH** | Department of Health (Victoria) |
| **DOHA** | Department of Health & Aging (Commonwealth) |
| **DoJ** | Department of Justice (Victoria) |

| | |
|---|---|
| **DoH** | Department of Health (Victorian) |
| **DSM** | Diagnostic Statistical Manual |
| **ECEC** | Early Childhood Education and Care |
| **ECIS** | Early Childhood Intervention Service |
| **ESL** | English as a Second Language |
| **DIAC** | Department of Immigration and Citizenship (Commonwealth) |
| **FaCHSIA** | Families, Housing, Community Services and Indigenous Affairs (Commonwealth) |
| **HACC** | Home and Community Care |
| **HCWA** | Helping Children with Autism (Commonwealth) |
| **ICD** | International Classification of Disease |
| **ILP** | Individual learning Plan |
| **ISF** | Inclusion Support Facilitator |
| **MCH** | Maternal and Child Health |
| **NAC** | National Autism Centre (USA) |
| **NAS** | National Autistic Society (United Kingdom) |
| **OCD** | Obsessive-Compulsive Disorder |
| **OPA** | Office of the Public Advocate |
| **OT** | Occupational Therapist |
| **PDDs** | Pervasive Developmental Disorders |
| **PDD-NOS** | Pervasive Developmental Disorder – Not Otherwise Specified |

| | |
|---|---|
| **PEP-3** | Psycho-Educational Profile- Third Edition |
| **PSFO** | Pre-School Field Officer |
| **PT** | Physiotherapist |
| **RANZCP** | The Royal Australian and New Zealand College of Psychiatrists |
| **SCS** | Specialist Children's Services |
| **SDS** | Special Development School |
| **SEAS** | Special Entry Access Scheme **SP** Speech Pathologist |
| **SSG** | Student Support Group |
| **SSSO** | School Support Services Officer |
| **SWC** | Student Welfare Coordinator |
| **VABS** | Vineland Adaptive Behavioural Scales |
| **VCAT** | Victorian Civil and Administrative Tribunal |
| **VELS** | Victorian Essential Learning Standards |
| **VEYLDF** | Victorian Early Years Learning and Development Framework |
| **VTAC** | Victorian Tertiary Admissions Centre |
| **WHO** | World Health Organisation |
| **WAIS** | Wechsler Adult Intelligence Scale |
| **WISC** | Wechsler Intelligence Scale for Children – Fourth Edition |
| **WPPSI** | Wechsler Preschool and Primary Scale of Intelligence |

# Glossary of Terms

**Asperger's Disorder (also referred to as Asperger's Syndrome)**

A pervasive developmental disorder defined by impairments in social interaction and restricted repetitive & stereotyped patterns of behaviour, interests and activities. Individuals with Asperger's Disorder do not have significant delays in cognitive or language development. However, social impairments generally affect the social use of language (pragmatics).

**Attention-Deficit/Hyperactivity Disorder (ADHD)**

A childhood-onset disorder with three main subtypes; inattentive hyperactive and mixed (where both inattention and hyperactivity-impulsivity are significant features), The core symptoms include difficulty in maintaining attention, distractibility, impulsivity and hyperactivity.

**Augmentative and Alternative Communication (AAC)**

The use of visual supports (objects, photos, boardmaker™ pictures etc.) or unaided systems (key word signs or gestures) to help individuals with language difficulties communicate more effectively.

**Autism**

A pervasive developmental disorder defined by impairments in social interaction, communication, and restricted, repetitive & stereotyped patterns of play and behaviour.

**Autism Diagnostic Interview-Revised (ADI-R)**

A structured parent interview developed by **Rutter, Le Couteur and Lord (2003).** Composed of 93 items, the ADI-R focuses on three domains: language/communication, reciprocal social interactions and restricted, repetitive, and stereotyped behaviours and interests. The ADI-R can be used with children and adults.

**Autism Diagnostic Observation Schedule – 2 (ADOS-2)**

A semi-structured, standardised assessment of communication, social interaction, and play developed by Lord, Rutter, DiLavore & Risi (2000). The ADOS-2 is suggested as a complementary instrument to the ADI-R. This play based session takes approximately one hour to complete

**Autistic Savant**

An individual with autism who displays an exceptional talent or skill (e.g. musical or artistic ability). A recent study (Howlin et al., 2009) showed that approximately one third of individuals with autism had either a savant skill based on parental report or an exceptional cognitive skill. Howlin et al., (2010) also found that no individual with a non-verbal I.Q. below 50 met the criteria for a savant skill suggesting that the much-used term of ‘‘Idiot Savant’’ is misleading.

**Autistic Spectrum Disorder**

The proposed change to DSM-5 diagnostic criteria due for release in 2013 with two domains that include; social communication deficits, and restricted and repetitive patterns of behaviour, interests and activities.

**Autistic Spectrum Disorders (ASDs)**

A recent term that typically includes Autistic Disorder, Asperger’s Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

**Childhood Autism Rating Scale (CARS)**

A five-item behaviour rating scale developed by Schopler et al. (1980) that rates severity of autism symptoms based on direct observation by a professional. The child is rated from one-four on a particular characteristic, ability, or behaviour and includes Relationships with People, Imitation, Affect, Use of Body, Relation to Non-human Objects, Adaptation to Environmental Change, Visual Responsiveness, Auditory Responsiveness, Near Receptor Responsiveness, Anxiety Reaction, Verbal Communication, Nonverbal Communication, Activity Level, Intellectual Functioning, and the clinician's general impression.

**Childhood Disintegrative Disorder (Heller’s syndrome)**

A rare pervasive developmental disorder that affects more males than females with onset of symptoms typically occurring between the ages of three and four. The disorder is characterized by apparently normal development for at least the first two years after birth followed by a significant loss of previously acquired skills in at least two of the following areas: expressive or receptive language, social skills or adaptive behaviour, bowel or bladder control, play and motor skills. In addition to regression, the child must also display impairments in at least two of the following areas: social interaction, communication and restricted, repetitive, and stereotyped patterns of behaviour, interest, and activities (APA, 2000). When symptoms are fully established, Childhood Disintegrative Disorder is almost indistinguishable from autism.

**Co-morbid Condition**

The presence of more than one concurrent diagnosis. Individuals with an ASD may have one or more additional diagnoses, such as ADHD, Tourette's Syndrome or Epilepsy.

**Developmental Behaviour Checklist (DBC)**

A 96-item checklist developed by Einfeld and Tonge (2002) to assesses a broad range of behavioural and emotional disturbances in children and young people (aged 4 - 18 years) with a developmental disability. Each item questions the presence of a particular emotional or behavioural problem over the previous six months. It uses a three point likert scale to provide a Total Behaviour Problem Score and five subscales: Disruptive/Antisocial, Self absorbed, Communication Disturbance, Anxiety and Social Relating. Clusters of symptoms indicative of ADHD, depression, anxiety and psychosis and an autism screening algorithm are also provided.

**Developmental delay**

Children under the age of six with developmental and learning problems are usually described as having a developmental delay rather than an intellectual disability which is the term used when children are older and can be tested on formal cognitive assessments. The majority of young children with autism (approximately 70%) also have a developmental delay and typically have an uneven profile of abilities. While young children with ASDs can be difficult to assess using standardised cognitive assessments, there are play-based developmental assessments designed specifically for very young children (e.g. Psycho-Educational Profile) which provide information about a child’s current developmental strengths and weaknesses.

**Diagnostic and Statistical Manual of Mental Disorders (DSM)**

Produced by the American Psychiatric Association the DSM contains descriptions, symptoms, and other criteria for diagnosing mental disorders. DSM is the diagnostic system commonly used in Australia. The last major revision was the fourth edition, text revised DSM-IV-TR), published in 2000. The fifth edition (DSM-V) is currently in the consultation and planning stage, and is due for publication in May 2013.

**Dual disability**

Individuals who have an intellectual disability and mental illness

**Early Childhood Intervention (ECI)**

ECI describes a range of services and supports provided to young children with developmental disabilities (0-6 years) and their families to improve the participation and functioning of the children and promote child and family well-being.

**Expressive Language**

The use of spoken language.

**High Functioning Autism (HFA)**

Individuals with autism who have an I.Q in the normal range

**Intellectual Disability (ID)**

Individuals with an I.D. have an IQ of 70 or less obtained from a standardised intelligence test and significant difficulties with everyday life skills, or adaptive behaviour.

**International Classification of Diseases (ICD) of the World Health Organization**

The European system used to classify diseases and disorders. The current edition is ICD-10 (WHO, 1992).

**Neurotypical**

A term sometimes used for individuals who do not have an ASD.

**Obsessive-Compulsive Disorder (OCD)**

A disorder characterised by obsessions (recurrent persistent thoughts, impulses or images) and/or compulsions (repetitive behaviours such as checking or mental acts such as praying, or counting).

**Occupational Therapist (OT)**

Health professionals trained to enable people to participate fully in the activities of everyday life. OTs modify the environment, or use specific activities to enable individuals to do things that will enhance their ability to participate.

**Pervasive Developmental Disorder (PDD)**

A term used to describe a group of five conditions, including Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) , Rett's Disorder and Childhood Disintegrative Disorder (DSM-IV-TR, 2000).

**Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)**

PDD-NOS, sometimes described as atypical autism (WHO, 1992) is a diagnosis given to individuals with a pervasive developmental disorder whose clinical symptoms are not better described by one of the other categories. This may be because of the age of onset, or because the individual does not have the key symptoms of other pervasive developmental disorders. Because of the lack of clear criteria, this diagnosis is often misunderstood and therefore is sometimes given when there is insufficient information, when the developmental history is unreliable, to describe a ‘milder’ form of autism or as a provisional diagnosis. DSM-IV-TR describes PDD-NOS as a severe impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interests and activities (APA, 2000).

**Physiotherapist**

A health professional trained to use a variety of techniques to help muscles and joints work to their full potential. Physiotherapists also provide rehabilitation and preventative advice.

**Psychiatrist**

A qualified medical doctor who has obtained additional qualifications to become a specialist in the diagnosis, treatment and prevention of emotional problems and mental illness.

**Psychologist**

A professional trained to understand human behaviour; the way people think, feel and learn. Psychologists use a range of strategies and interventions to work with individuals with behavioural or mental health problems such as anxiety and depression.

**Restrictive interventions**

Restrictive interventions include seclusion, mechanical and chemical restrains defined in the Disability Act (2006)

**Special Entry Access Scheme (SEAS)**

The Special Entry Access Scheme (SEAS) through the Victorian Tertiary Admissions Centre (VTAC) for applicants who have experienced educational disadvantage (e.g. as a result of a disability or medical condition). SEAS allows course selection officers to recognise that results or educational progress may have been affected by circumstances in the SEAS application, and to consider the effect of those disadvantages.

**Shared and Supported Accommodation**

Shared and supported accommodation (formerly known as a Community Residential Unit) is a group home for individuals with disabilities. Shared Supported Accommodation is for people who require rostered support and is targeted to people with a disability with the highest support needs.

**Special Developmental School (SDS)** An educational setting for school-aged children with an I.Q. of less than 50.

**Special Education Teacher**

A qualified teacher who has obtained additional qualifications to become a specialist in the education of children and/or young people with a developmental delay or disability.

**Specialist School**

An educational setting for school aged children with an I.Q. between 50 and 70.

**Speech Pathologist**

A health profession trained to diagnosis, manage and treat individuals who are unable to communicate effectively or who have difficulty with feeding and swallowing.

**Vineland Adaptive Behavioural Scales (VABS-II)**

A clinical instrument developed by Sparrow, Cicchetti, & Balla (2005) designed to assess the communication, daily living skills, socialisation, and motor skills of individual's between 0-90 years of age.

**Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV)**

A clinical instrument for assessing the intellectual functioning of children aged 6 to 16 years 11 months. The individual's performance on various sub-tests is summarised in three components – Verbal IQ, Performance (non-verbal) IQ and an overall IQ score.

**Wechsler Preschool and Primary Scale of Intelligence – Third Edition (WPPSI-III)**

A clinical instrument designed to assess IQ for children ages 2 years 6 months to 7 years 3 months.

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