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EDITORIAL

Kaye Horley, PhD
Editor

Autism spectrum disorders (ASDs) are considered the most common of the pervasive neurodevelopmental disorders. The first nosological category, such as DSM-1 (American Psychiatric Association, 1952), classified children with autism as having childhood schizophrenia. The most recent, DSM-5 (American Psychiatric Association, 2013), places children on a spectrum, inclusive of a broader category of ASD, characterised by communicative, social and behavioural difficulties. An Australian national survey (Australian Bureau of Statistics, 2012), indicated a prevalence of 0.5% (115,400), with a significantly greater incidence in males (0.8%) compared to females (0.2%).

The aetiology of autism is unknown, however, modern theories have come a long way since Kanner (1943) laid the blame on parents. In this issue of the Australian Clinical Psychologist, current biological theories are discussed by Saunders and Waldie. In examining the neural basis of autism, they highlight the evidence for a strong genetic component, although the contribution is small. Since understanding the brain leads to understanding the mind, the authors place emphasis upon brain anatomical and functional differences in ASD in comparison to healthy populations, and relate these anomalies to specific social, cognitive and behavioural deficits. The added complexity of comorbidity is additionally considered, particularly those of ADHD and OCD.

Early detection of ASD is essential to enable provision of interventions as early as possible. Statham provides an overview of a number of common standardised tests, describing the purpose, range of behaviours and level of severity measured, target population, administration and scoring, reliability and validity and ease of use. Assessment is examined in relation to the more general developmental and intellectual impairments that may be associated with ASD by Paynter and Fothergill. Consideration is given to the social, communicative and behavioural deficits characterising ASD that present many challenges for clinicians conducting assessments in young children, and practical suggestions are provided.

School attendance presents new challenges for children on the autism spectrum. As Roberts emphasises, impaired functioning and problematic behaviours may result in a range of issues. These may include difficulties in understanding and learning, inability to fit in with peers, bullying, academic difficulties, poorer attendance rates and poorer post-school outcomes. Understanding the specific challenges faced by school-aged children allows for engagement in individualised behavioural interventions most effectively provided by a multidisciplinary team.

Socialisation deficits, particularly social reciprocity, are principle features of ASD, and may result in peer rejection, victimisation and loneliness, with resultant detrimental and challenging effects upon one’s sense of identity and social construction of the world. Interventions addressing such difficulties are essential. An innovative evidence-based program aimed at teaching social and emotional skills to children at the higher end of the spectrum is the internationally recognised Secret Agent Society program. As described by Beaumont, who developed the multi-faceted program, it entails various strategies tailored to engage and monitor the progress of children, and has a strong theoretical basis.

Although problems with ASD continue into adulthood, there is much less research focused on this age group. Notably, there is limited empirical research regarding psychosocial outcomes in higher functioning ASD adults. In PhD Spotlight, Zimmerman’s PhD seeks to redress this by examining such aspects as the relationship between the severity of ASD and functioning, the relationship between symptomatology and functioning including neurological, cognitive and emotional, and the development and testing of a psychosocial explanatory model. The consequence of impaired social functioning is typified in the problems adolescents and adults with ASD encounter in developing romantic relationships.

Collaboration with the autism community, those with ASD, their families and carers, should be inclusive in policy and service planning, but is not always apparent. An example of meaningful engagement between community and services was the formation of the Scottish Strategic Group for Autism, specifically formed to redress this imbalance. Robinson and Shankland report on the differing priorities of community and service planners, and highlight the ensuing benefits of the collaboration. We are very appreciative of Thomas in answering questions provided by Autism Spectrum Australia, giving us his personal story to help us understand the experience of someone with autism. His father, John, provides insight into his experience as a parent.

The outcome of a forum that provided the opportunity for early career qualified clinical psychologists to meet and discuss the key issues they face along with potential solutions, is reported by Csabony, and has implications for us all.

References


Editor: editor@acpa.org.au
From the President

Judy Hyde, PhD

Happy Birthday ACPA! April, 2015 celebrates the 5th anniversary of the foundation of ACPA. These have been important years in the history of clinical psychology in Australia. For the first time clinical psychology has had its own voice that speaks clearly about the importance of and value in training in producing well-qualified and capable clinical psychologists who offer safe and effective evidence-based services to the public with a high level of professionalism. The fact that qualified clinical psychologists have the highest level of training in psychology of any mental health professional, and need to be identified for the expert contribution they can make to the mental health of Australians, is becoming increasingly recognised at all levels of society.

ACPA celebrates this important milestone with the implementation of a Fellows program. This program recognises outstanding, exceptional and enduring contributions of members to ACPA and to clinical psychology. The current ACPA National Board has nominated all Directors of the Inaugural Board for Fellowship in recognition of their outstanding contribution to the establishment of ACPA and their ongoing work and commitment to the organisation. The Inaugural Board took on the task of establishing ACPA and developing the structures and procedures to create this wonderful organisation. This was an overwhelming amount of work undertaken with dedication, determination and commitment, flavoured by humour and driven by shared passion. Also being nominated for Fellowship by the National Board are Dr Cal Paterson and Mr Ben Callegari, whose gifts and skills established the first website and branded ACPA with the stylish, clean, fresh look we are so proud of. The National Board will hold a dinner to celebrate the achievements of these members in Sydney later in the year where the honour of Fellow will be bestowed and certificates presented.

Guidelines for the application process for the honour of Fellow of ACPA (FACPA) will be released, along with the forms. A Nominations Committee will also be established to review nominations for the membership status of Fellow and also to advise the Board on the required skills of Directors of the Board and identify members who may be suitable to serve on the Board in all its roles.

A further member benefit being implemented to celebrate ACPA’s fifth birthday is free membership for a year for any member who brings in a new fee-paying member. The Application for Membership form includes a space for the applicant to nominate a current Associate or Full Member for this benefit. The benefit can only be claimed once.

In keeping with our mission to promote high standards throughout the profession, ACPA will continue to encourage the Psychology Board of Australia (PBA) to simplify the pathways to registration and provide greater clarity of the routes that have led to the endorsement of unqualified clinical psychologists through specialist recognition of those who are qualified. With the large take-up of the 5 + 1 generalist registration program of training, the confusion over the different pathways to registration has increased, as has the size of the workforce. Australia has the largest per capita number of psychologists in the Western world; yet Australia’s standards of training, even with the 5 + 1 model, remain the lowest in the Western world. It is time to seriously consider raising standards in the best interests of the public.

Further in keeping with the mission of promoting recognition of the value and quality of training in clinical psychology, ACPA is in the process of developing and consulting on an application to the PBA for them to make a submission to grant qualified clinical psychologists specialist recognition. The membership of ACPA has embraced this application and provided support for the submission being made. The contribution of members to the process is very much appreciated and demonstrates the significance of the listserv yet again in forwarding our aims and objectives, as we reach out to members for information and receive overwhelming support.

This year again promises to be a time of change and development for the profession as the impacts of the recommendations of the National Commission into Mental Health are considered and implemented. This is likely to have far-reaching effects and ACPA wants to play a role in ensuring that specialist services are provided by those with the best training to deliver them. In change there is opportunity and we look forward to taking those opportunities we are presented to ensure the best utilisation of the expertise of qualified clinical psychologists.
Abstract

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition for which there is no known cause or cure. It is a highly variable disorder, the most prominent difficulties of which include aberrant behaviour, poor social skills and disrupted communication skills. Evidence suggests that the prevalence of ASD is steadily rising and this has led to widespread speculation and research concerning the causes of the disorder. Following about 50 years of intensive study, researchers now believe that autism is a complex disorder whose core aspects have distinct causes that often co-occur. Some of these distinct causes are the focus of this review. We focus on findings that suggest that children with ASD have larger overall brain volumes and differences in brain growth trajectory. By adulthood those with ASD have anatomical and functional abnormalities in prefrontal cortex, basal ganglia, temporal lobe, and the limbic system. Impairments in these areas, as well as under-connectivity between and within these brain regions, can lead to range of interrelated deficits in interpersonal interaction such as problems remembering and identifying people, the inability to perceive social cues, and misunderstanding nonverbal communicative cues such as gestures, facial expressions, and emotional prosody. The presence of comorbid conditions compounds these difficulties.

Background and Prevalence

Leo Kanner (1943) first described autism after observing a group of patients with similar impairments. The patients who he had seen in his clinic all exhibited: an inability to relate to people; failure to develop speech; abnormal responses to environmental objects and events, an obsessive desire for sameness; and excellent memory. Kanner labelled this condition ‘early infantile autism’. One year on, Hans Asperger (1944) described a group of children using similar terminology. In addition to these characteristics, however, he also noted that the children had developed normal language, but the content of their speech was slightly abnormal, tending to be pedantic. The symptoms characteristic of this higher functioning group became known as Asperger’s syndrome.

There have been recent changes to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013). According to the clinical manual, ‘Asperger’s syndrome’ no longer exists as a label to describe high-functioning autism. Instead, all individuals with autism are considered to lie on part of a spectrum, with very low functioning people on one end (who will be mute with general cognitive impairments) and high functioning people on the other end (who will have normal or higher IQ and difficulties with social interaction); all are considered under the umbrella term Autism Spectrum Disorders (ASDs). Here we use the term autism interchangeably with ASD to refer to all individuals on the spectrum.

The prevalence of ASD is estimated to be 60 in 10,000 (0.6%), with a male:female ratio of 4:1 (Fombonne, 2005). The prevalence of autism has been steadily rising (Atladóttir et al., 2007; Elsabbagh et al., 2012), with estimates from 4/10,000 to 66/10,000 over a ten year period (Hill, Zuckerman, & Fombonne, 2014) leading to widespread speculation concerning the factors that may be responsible.

Little is known about the underlying basis of comorbidity in autism. Data suggest approximately 28% have an additional diagnosis of ADHD and 41% to have anxiety (Simonoff et al., 2008). The presence of these additional conditions causes the individual pronounced distress and impairment (Leyfer et al., 2006). Those with additional
conditions are thought to have more severe symptoms, more pronounced social difficulties and are lower functioning that those with ASD alone (Kerns & Kendall, 2012).

**Genetic Inheritance**

*Greater total brain volume.* Magnetic Resonance Imaging (MRI) data reveals that by age two to four years, 90% of autistic children have a significantly larger average brain volume than neurotypical controls (Akshoomoff, Pierce, & Courchesne, 2002; Courchesne, 2004) This is particularly the case in the dorsolateral frontal cortex (Carper & Courchesne, 2005; Hua et al., 2013). The over-production of brain cells eventually slows down as the autistic child develops (Courchesne, Campbell, & Solso, 2011; Schumann et al., 2010).

In addition to MRI studies, autopsy data also reveals an excess of neurons in the prefrontal cortex among young children with autism (Stoner et al., 2014). Young children with autism also exhibit more cortical (18%) and cerebellar (39%) white matter than controls (Akshoomoff et al., 2002; Courchesne, 2004). Although the over-production of neurons is a normal feature of brain development, typical development involves the subsequent pruning of excess neurons and synapses. This is one of the general principles in brain plasticity, and the elimination of synapses coincides with increasing cognitive and motor skill in the typically developing child. In the case of autism, however, the normal pruning of excess neurons and their connections appears to be faulty, leading to abnormal white matter connectivity.

Taken together, the particular neural defects that cause early brain overgrowth may underlie the neural basis of autism. Although it is unclear what causes this grey and white matter overgrowth, one finding relates to fewer and/or abnormal connections between areas of the brain involved in inhibitory control and face recognition, namely the frontal cortex, temporal cortex, and amygdala.

*Inhibitory control and brain connectivity.* Executive functioning deficits and social difficulties seen in autism are often associated with problems in the frontal cortex and with the circuits leading to and from the frontal lobe.

Executive functions include planning, working memory, attention, problem solving, verbal reasoning, mental flexibility, task switching, and monitoring of actions, and inhibitory control. Inhibitory control allows individuals to withhold dominant responses or ignore distracting stimuli in order to give an appropriate response. In real-world situations inhibitory control is important as it stops us from performing a potentially inappropriate action when given the urge (e.g., an extreme emotional outburst). Withholding inappropriate urges is a necessary criterion for performing socially appropriate behaviour.

Inhibitory control deficits and repetitive behaviour are part of the core features of autism. The communication and integration of specific brain networks are vital in order for the successful execution of motor and executive functions. Inhibitory control, in particular, requires synchronisation of neuronal networks mostly in the frontal lobe (anterior cingulate gyrus, middle cingulate gyrus) and posterior areas of the brain such as the striatum, basal ganglia, and the insula (which is folded deep within the lateral sulcus, separating the temporal lobe from the frontal lobes).

Research using a variety of techniques has shown that the connectivity of posterior regions to prefrontal cortex is atypical in people with ASD. For example, diffusion tensor imaging (DTI), which measures white matter connectivity, indicates that those with autism show abnormal anatomy of the frontal-striatal white matter tracts (Langen et al., 2014). Functional MRI imaging (fMRI), able to measure functional connectivity between brain areas during task performance, corroborate the structural findings. The inhibitory circuitry is under-activated and less synchronised in individuals with autism compared to neurotypical controls (Kana, Keller, Minshew, & Just, 2007). Resting state functional MRI or electroencephalography (EEG) recording can measure cortical synchronisation in the absence of task performance. Abnormal resting state cortical connectivity between frontal and posterior regions has similarly been found in individuals with autism (Cherkassky, Kana, Keller, & Just, 2006; Murlis, Webb, Greenson, & Dawson, 2007).

Though there is great variability in symptom severity and intellectual functioning in ASD, all individuals with autism have social difficulties involving eye contact, reciprocal interactions, and responding to emotional cues. The following section describes research that suggests that these social difficulties may be the result of the nature of face processing in autism. The brain areas involved in our ability to attend to and process information from faces (fusiform face area and amygdala) may be impaired in people with autism.

*Face processing and brain connectivity.* Children with ASD perform worse on face processing tasks including face discrimination and face recognition. In very young children, the ability to use facial information (for example, engaging in joint attention) is considered a critical early marker of ASD (Zwaigenbaum, Bryson, Rogers, Roberts, Brian, & Szatmari, 2005). Individuals with ASD also process faces using abnormal strategies. They pay less attention to core features of the face like the eyes and nose relative to typically developing adults (Dawson, Webb, & McPartland, 2005).

In a series of fMRI experiments, Robert Schultz discovered that, at the basic neural level, a face is just another object for people with autism. He typically asked participants to press a button to indicate whether pairs of faces or pairs of objects (e.g., cups, chairs) were the same or different. The findings revealed that neurotypical individuals primarily use the fusiform gyrus (known as the fusiform face area) when processing faces and the inferior temporal gyrus to process objects (Dawson, Webb, & McPartland, 2005).

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In addition to neglecting the fusiform face area when responding to faces, individuals with autism have impaired connectivity between the right fusiform gyrus and the amygdala. The amygdala itself also is abnormally large in autistic children (Schumann et al., 2010). The amygdala measures just an inch long, resides deep inside the brain and is shaped like an almond. It plays a significant role in facial expression and emotion processing (Bauman & Kemper, 2003; Skuse, 2003) and, if the amygdala is damaged, there is difficulty recognizing strong emotions such as fear (Adolphs, Tranel, Damasio, & Damasio, 1994). In neurotypical individuals, the amygdala is significantly more activated when a fearful face is perceived as opposed to a neutral face (Morris et al., 1998).

Kleinhan and colleagues (2008) found that the degree of social impairment in those with autism was associated with decreased connectivity between the amygdala and the fusiform face area. Social impairment was measured with the Autism Diagnostic Interview-Revised (ADI-R) social score. This negative correlation between amygdala- fusiform face area connectivity and the ADI-R score (Kleinhan et al., 2008) suggests that abnormalities in the connections between the emotional centre of the brain and the face processing area plays an important role in the social skills difficulties in autism.

### Comorbidity in Autism

Comorbidity is defined as the co-occurrence of two or more conditions in the same individual (APA, 1994). Physically, ASD is associated with higher rates of epilepsy, sleep disorder, gastrointestinal disorders and autoimmune conditions (Matson & Goldin, 2013). Additional neuropsychological conditions like Attention Deficit Hyperactivity Disorder (ADHD) and anxiety (particularly Obsessive Compulsive Disorder (OCD)) are known to affect between 50–70% of individuals with ASD (Ghaziuddin & Zayfar, 2008). While little is known about the underlying basis of comorbidity, the presence of these additional conditions causes the individual pronounced distress and impairment. For example, those with additional conditions are thought to have more severe symptoms, more pronounced social difficulties and are lower functioning that those with ASD alone (Kerns & Kendall, 2012).

**ADHD and ASD.** There are many overlapping symptoms between the two disorders including: attention difficulties, hyperactivity, impulsivity (Hays, Reas, & Shaw, 2002), social skill deficits (Cervantes et al., 2013; Demopoulos, Hopkins, & Davis, 2013), behavioural issues (Mayes, Calhoun, Mayes, & Moltoris, 2012) and both are associated with differences in the prefrontal cortex (Johnson, 2012).

Previously, the DSM-IV (APA, 1994) did not allow the co-diagnosis of ASD and ADHD. Researchers working on the latest version of the DSM (DSM-5; APA 2013) removed this prohibition of co-morbidity. Thus, individuals with autism spectrum disorder may also have a diagnosis of ADHD. A better understanding of the aetiology of autism and its associated conditions will help with earlier diagnosis and treatment strategies.

Atypical connectivity may underlie many difficulties seen in autism. Interestingly, the fronto-striatal pathway is also impaired in individuals with ADHD (Wu, Gau, Lo, & Tseng, 2014) and executive functioning deficits are among the core features of ADHD. As there are high rates of comorbidity between autism and ADHD (Talkowski, Minkel, & Gusella, 2014) we now need to know how this pathway functions in individuals with just one or both conditions (Vissers, Cohen, & Geurts, 2012).

**ASD and OCD.** OCD in ASD is common (37% of those with ASD have OCD; Leyfer et al., 2006), and contributes to a reduced quality of life. There are numerous similarities between OCD and ASD. As such, behaviours like repetition feature in the diagnostic criteria for both conditions. People with OCD and ASD may both have obsessions about a particular event occurring (for example, repetition of certain numbers, like car registrations). The phenotype of repetitive behaviour is strongly linked to the certain brain pathways. Changes in the striatum have been linked to repetitive behaviour seen in ASD (Langen et al., 2012). There is also consistent support for the involvement of orbito-frontal striatal systems in OCD (Harrison et al., 2013) and in ADHD (Cubillo, Halari, Smith, Taylor, & Rubia, 2012). Taken together, there seems to be a common brain basis to the repetitive behaviour seen in all three disorders.

More research into comorbidities is needed so that clear boundaries can be established between those behaviours that are distinct from the condition of ASD (that represent a clearly different disorder) and those that are manifestations of ASD itself. There is no treatment for ASD. However, there are well established treatments for conditions such as OCD or ADHD. Identifying behaviours that are indeed manifestations of comorbid conditions will allow for appropriate treatment of these behaviours. This will greatly reduce the distress that arise from symptoms of comorbid conditions ASD.

### Summary and Conclusions

Autism is a heritable and lifelong neurodevelopmental disorder with an increasing prevalence. Although genetic factors play an important role in autism aetiology, many different genes can contribute to the ASD phenotype. The most robust neurological finding to account for autism is greater brain volume. The early brain overgrowth and related dysfunction is most strongly evident in the prefrontal cortex. Other sites of regional gray and white matter overgrowth include the temporal cortex and amygdala.

Many of the characteristic features of ASD can be described in terms of specific cognitive deficits, which together conspire to make it hard to communicate effectively and to develop and maintain social relationships. Abnormal inhibitory control (of motor and general cognitive skills), and atypical face processing, are thought to underlie such features. These, in turn, can be partially explained by atypical connectivity between the frontal lobe and striatum (including basal ganglia), and between the temporal cortex and amygdala. Interestingly, many of the brain networks involved in autism are similar to those that are implicated in common coexisting conditions like ADHD and OCD. Identifying the underlying brain networks of the difficulties seen in ASD (and especially those that share a common basis with other conditions) will allow for more appropriate treatment options.
References


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Autism Assessment Measures

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Autism is defined as a neurodevelopmental disorder characterised by deficits in social interaction and communication (specifically, in social-emotional reciprocity, non-verbal communication, and establishing, maintaining and understanding social relationships) along with the presence of restricted, repetitive patterns of behaviour, interests, or activities (specifically, stereotyped/repetitive motor movements, use of objects, or speech; insistence on sameness and inflexibility with routines; excessively intense or focused interests that are highly restricted and fixated; and hyper- or hypo-reactivity to or unusual interest in sensation). The deficits must be longstanding, with onset in the early developmental period; they must cause clinically significant functional impairment in multiple contexts; and must be differentiated from other developmental disorders (APA, 2013).

Establishing a diagnosis of autism requires knowledge about current and past behaviour and an understanding of the individual's developmental trajectory. The two primary methods for collecting this information include self- and other-reports, and direct observation. What follows is a summary of the most commonly used tools, starting with the gold standard measures: Autism Diagnostic Interview–Revised (ADI-R; self/other report; Rutter, Le Couteur, & Lord, 2008) and the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; direct observation; Lord et al., 2012a; Lord, Luyster, Gotham, & Guthrie, 2012b), followed by the Social Responsiveness Scale (SRS-2; Constantino & Gruber, 2012), The Childhood Autism Rating Scale (CARS-2; Schopler, Van Bourgondien, Wellman & Love, 2010), and the Autism Asperger Diagnostic Scale (RAADS-R; Ritvo, Ritvo, Guthrie, Yuweiler, Ritvo, & Weisbende, 2008; Ritvo et al., 2011).

The Autism Diagnostic Interview–Revised

The ADI-R is a semi-structured, standardised clinician administered interview, which is conducted with the client’s parent/carer and is suitable for all clients with a minimum mental age of 2 years. The 93 items are divided into eight main sections: (1) background about the client’s family, education, diagnoses and medications; (2) the client’s behaviour and the current concerns of the interviewee; (3) early development and key developmental milestones; (4) language acquisition; (5) language and communication functioning; (6) social development and play; (7) interests and behaviours; (8) behaviours of clinical importance (gait, aggression, self-injury, hyperventilation, and epileptic features).

The interviewer rates each question on a 4-point scale: 0 (behaviour not present) to 3 (definite abnormality), and records detailed behavioural examples that substantiate the score for each item. Administration and scoring time ranges from between 1 ½ to 2 ½ hours. There are two main scoring algorithms: the Diagnostic Algorithm (DA) which focuses on developmental issues, and the Current Behaviour Algorithm (CB) which focusses on behaviour occurring during recent months. The DA estimates severity and likelihood of meeting diagnostic criteria for ASD (ICD-10 and DSM-IV), while the CB estimates functioning in multiple areas and can inform treatment planning.

In the ADI-R Manual the authors provide statistical data that demonstrates good internal reliability for all domains (social .95; restricted and repetitive behaviours .69; verbal .85; and communication .84) (Lord et al., 1994), and high test-retest reliability (.93 -.97). Specificity and sensitivity are both high (over 90%) for older children (Lord, Storoschuk, Rutter, & Pickles, 1993) but are less adequate for younger children (Kim, Thurms, Shumway, & Lord, 2013). More recently, revised algorithms have been developed (Kim et al., 2013; Kim & Lord, 2012) that have improved diagnostic validity for toddlers and young preschoolers from 12 to 47 months. Also, both research and clinical cut-offs are now available for this age group, along with three ranges of concern (little-to-no; mild-to-moderate; moderate-to-severe), which reflect severity of symptoms (Kim et al., 2013).

The ADI-R manual (60 pages) is clearly presented and easy to follow. After an introductory chapter, the manual discusses the basic concepts of ADI-R interviewing (chapter 2), the administration protocol and coding instructions (chapter 3), the diagnostic algorithms and interpretation (chapter 4). The final chapter provides information about the development of the interview and the psychometric research.

The record form is a substantial size (87 pages) because it has one item per page, and each item has an explanation of what it is measuring, and verbal prompts are provided, as well as the scoring criteria. Approximately 50% of each page consists of white space (for writing notes), which helps with visual clarity.

Autism Diagnostic Observation Scale

The ADOS-2 (Lord et al., 2012a; Lord et al., 2012b) is a semi-structured, standardised, and interactive assessment of communication, social interaction and behaviour. It consists of

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five modules. The Toddler Module (12-30 months) and Module 1 (31 months and older) are used with children who have no speech at all or who are able to use simple phrases. Module 2 is used with children of any age who are not verbally fluent, but can use phrase speech, and with children younger than 3 years who are verbally fluent. For older individuals who are verbally fluent, Modules 3 (children and adolescents up to age 16) and 4 (older adolescents and adults) are used.

For all modules the assessment is conducted by the examiner engaging the client in several social interaction activities, and coding their responses using a 4-point scale (0 = no evidence of abnormality for the specified behaviour; 1 = behaviour is mildly abnormal or slightly unusual; 2 = the behaviour is definitely abnormal; or, 3 = the behaviour is markedly abnormal). Some examples of the types of activities in Module 3 include engaging with the client in structured (constructing an object) and unstructured (use of different toys/objects) tasks, and joint interactive play (having the client tell a story from sequential pictures and from cartoons; asking the client specific questions about relationships and friendships).

In a review of the ADOS-2, McCrimmon (2014), reported that Cronbach’s alpha values were consistently high for the Social Affect domain (communication, reciprocal social interaction; >.85) and moderate for the Restrictive and Repetitive Behaviour domain (.47 – .66), indicating acceptable internal consistency. Test-retest reliability for modules 1 to 3 was adequate (.68-.92), as was the Toddler module (.68 -.88). Inter-rater reliability for the coding of items was high (> 70%), agreement around diagnosis was even higher (92% – 98% for Modules 1 to 3; 87% - 97% for the Toddler Module) (McCrimmon, 2014). Content, construct and predictive validity were all acceptable. Recent revisions to the algorithm for Module 4 showed good specificity (89.6%) and adequate specificity (72.2%) and the authors suggest using a cut-off score of 10 to increase specificity (91%), but acknowledge that a potential loss of sensitivity occurs (71-79%) when comparing ASD and non-ASD individuals (Hus & Lord, 2014).

The ADOS-2 Manual has two parts. Part I (443 pages) consists of detailed information about administration, coding, and interpretation procedures for the five modules. Each module is colour coded to match the record forms for each module. Part II (360 pages) of the manual focuses on the use of the Training Video Program (now available in DVD format). Part II also includes the descriptions and scored record forms for 6 of the 10 cases that are included in the training program.

Social Responsiveness Scale, Second Edition

The SRS-2 (Constantino & Gruber, 2012) is a clinician-administered rating scale which assesses the frequency, intensity, peculiarity and duration of behaviours characteristic of ASD. It is suitable for individuals six years and older with an IQ of 80+. There are two versions; the standard version (CARS2-ST) which can be completed during a clinical session based on information provided by a parent or carer, or from direct observation; and the high functioning version (CARS2-HF) which requires both information from someone who can describe the person’s behaviour in multiple settings, and a direct observation by the clinician. There is also a parent/carer form for obtaining qualitative information about the individual’s behaviour. It is not scored and is used as a source of supplemental information.

The two forms each have 15 items (e.g., relating to people; emotional response; verbal and non-verbal communication; object use) that are rated on a 1 (no difficulty; age-appropriate) to 4 (severely abnormal response) scale. Item scores are summed to obtain a total raw score (range = 15 – 60) with higher scores reflecting a greater number of autism-related behaviours. Cut-off scores are used to inform categories of severity (‘likely nonautistic’; “mild-to-moderate level of behaviours related to autism”; “severe level of behaviours related to autism”). T-scores enable comparison of the client’s behaviours with a normative group of individuals with ASD.

Both forms of the CARS-2 have good reliability (Cronbach’s alpha of .93 and .96) and the HF version also has good inter-rater reliability (.95) (Vaughan, 2011). Adequate concurrent validity was demonstrated by correlating the CARS2...
total scores with the ADOS (ST: \( r = .79 \); HF: \( r = .77 \)) and the Autism Behavior Checklist (ST: \( r = .67 \)) (Vaughan, 2011).

The manual (109 pages) provides clear instructions for administration, scoring and interpretation. The worked examples of both the ST and HF forms are useful guides. The five-page record forms are coloured coded (blue for ST, green for HF), clearly laid out, easy to follow with concise instructions, and each question has adequate space for the clinician to write notes. Item raw scores are transferred to the front page, summed, and then T-scores are calculated using the conversion table provided. A rating scale for severity, based on the total raw score is also provided.

The Ritvo Autism Asperger Diagnostic Scale-Revised

The RAADS-R (Ritvo et al., 2008; Ritvo et al., 2011) has been designed as a screening tool for use with adults who have average or above average intelligence. It consists of 80 items, in four domains (1) Social Relatedness (23 items); (2) Circumscribed Interests (28 items); (3) Sensory Motor (18 items); and (4) Social Anxiety (11 items). Sixty-four of the items describe specific symptoms of ASD and are answered on a 0 (never true) to 3 (true now and when I was young) scale. The remaining 16 items reflect non-symptomatic behaviours and are reverse scored (0 true now and when I was young to 3 never true). A total score is obtained by summing the items, and a score of 65+ suggests a diagnosis of ASD. However, scores of <65 do not exclude the possibility of ASD and the authors emphasise favouring clinical judgement over RAAD-R scores, for low scores, when ASD symptoms are present.

The authors report good internal consistency (\( \alpha .87 \) – .95), high sensitivity (97%), specificity (100%) and test-re-test reliability over 10 – 15 months (\( r = .98 \)) (Ritvo et al., 2011). Thus the RAADS-R is a psychometrically sound tool that can accurately discriminate between those with a DSM-IV-TR diagnosis of ASD and those without.

The RAADS-R is a self-report measure which is easy to administer and score. The authors provide a copy of the scale and the scoring guidelines in their paper (Ritvo et al., 2011).

Conclusion

The assessment of ASD is a complex process which involves identifying deficits in reciprocal social communication and social interaction, and exploring patterns of behaviour, interests and activities, and evaluating the extent to which they are excessively restricted and repetitive. The process of diagnosis relies heavily on drawing together information from multiple sources including the DSM-5 criteria, reports from parents and teachers, and self-reports, and observational measures. In addition to using specific ASD measures such as those discussed above, a comprehensive assessment of ASD should also include assessment of other key areas of functioning including, intellectual and academic abilities, adaptive behaviour and language skills.

References


Children with ASD are more vulnerable to challenging diagnostic criteria (American Psychiatric Association, 2013). Hypersensitivity to sensory input, such as sensitivity to sound, is common (Ben-Sasson, et al., 2009) and acknowledged in the diagnostic criteria (American Psychiatric Association, 2013). Children with ASD are more vulnerable to challenging behaviour (e.g., non-compliance and/or difficulties with emotional regulation) than other groups, such as children who are typically developing, or who have other disabilities such as Down syndrome (e.g., Eisenhower, Baker, & Blacher, 2005). Co-morbidities are also common including intellectual impairment (see Elsabbagh, et al., 2012, for estimates in epidemiological studies), mood disorders (e.g., Simonoff et al., 2008), and medical conditions such as epilepsy (e.g., Mannion & Leader, 2014). Challenges with executive functioning (i.e. suppressing responses, difficulties with keeping/using information and changing strategies/shifting set), have also been well-documented in individuals with ASD (Geurts, Vries, & Bergh, 2014). These common features and co-morbidities can raise challenges around conducting a valid assessment.

Typically-developing children are often keen to please assessors, whereas children with ASD may not appear this way, and difficulties with understanding what is being asked of them or challenges in social understanding, may lead to children with ASD being more easily frustrated and harder to engage (Akshoomoff, 2006). In addition, difficulties with communication may impair children’s ability to understand task requirements. In line with this, previous research (e.g., Dawson, Soulieres, Gernsbacher, & Mottron, 2007; Grondhuis & Mulick, 2013) has found children with ASD tend to perform better on non-verbal assessments (e.g., Leiter International Performance Scale-Revised; Roid & Miller, 1997) than more verbally-based assessments of intellectual functioning (e.g., Wechsler Intelligence Scales for Children – Fifth Edition [WISC-V]; Wechsler, 1991; Stanford-Binet – Fifth Edition [SB-V]; Roid, 2003).

Young children with ASD also show difficulties with imitation relative to their typically-developing peers (e.g., Rogers, Hepburn, Stackhouse, & Wehner, 2003) and proto-declarative pointing, that is pointing for purposes other than requesting (Leekam, López, & Moore, 2000; Sigman, Mundy, Sherman, & Ungerer, 1986). These characteristics may limit a child with ASD’s ability to understand or respond to items in some assessments, such as imitating block constructions in a
particular way (e.g., in the WISC-IV; Wechsler, 2003; and Mullen Scales of Early Learning [MSEL]; Mullen, 1995), or pointing to matching pictures (e.g., MSEL), or a picture of a named item (e.g., Peabody Picture Vocabulary Test; Dunn & Dunn, 1997). Challenging behaviour may also make conducting an assessment more difficult, and higher rates of challenging behaviour and lower engagement have been linked to poorer test performance in children with ASD (Akshoomoff, 2006). Finally, difficulties with executive functioning (e.g., difficulties shifting set) as well as restricted thinking (diagnostic criteria) may present challenges in assessments where the same materials are to be used in different ways (e.g., stacking blocks vs. imitating block constructions in the MSEL).

**Standardised Cognitive and Developmental Assessments**

In clinical practice, given the above challenges, it is perhaps not surprising that one often encounters queries around the appropriateness of using standardised assessments, particularly with young children with ASD. Indeed, some have questioned the validity of standardised assessments as a whole with young children and advocated for alternative assessment approaches (e.g., Neisworth & Bagnato, 2004). Evidence for the validity of assessments for young children with ASD, using intellectual assessment as an example, may be seen in findings that intellectual quotients (IQs) of children with ASD are stable from the preschool years (e.g., Dietz, Swinkels, Buitelaar, Daalen, & Engeland, 2007; Lord & Schopler, 1989) and that IQs in the average range in children with ASD are stable into adulthood (Howlin, Savage, Moss, Tempier, & Rutter, 2014). However, given the challenges above, careful consideration of the most appropriate assessment, advance preparation, and work in session to build and maintain attention and engagement is required to give the best opportunity for a valid assessment.

**Choosing an Appropriate Developmental or Cognitive Assessment**

Factors to consider when choosing an appropriate general assessment (e.g., cognition, development level, educational skills), in addition to the referral question, include the child’s chronological and mental age, verbal ability, and test-taking skills (e.g., pointing). Test characteristics to consider may include whether the age range starts at infancy or tasks are understandable to preschool children with a mental age of less than two years, whether instructions for non-verbal tests may be demonstrated by the examiner, flexibility of item administration, and whether lengthy discontinuation procedures are avoided. A summary of common intellectual/developmental assessments and the factors to consider as an example, adapted from Brassard and Boehm (2007), may be seen in Table 1. Intellectual and developmental assessments of children with ASD may be required for example, to ascertain whether children fulfill criteria for school placement, for differential diagnosis, or to provide information on developmental level that may inform functional behavioural assessment and setting of developmentally-appropriate behavioural expectations.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Clinical Characteristics of Commonly used Intellectual/Developmental Assessments *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test</td>
<td>Materials include toys</td>
</tr>
<tr>
<td>Bayley Scales of Infant Development – Third Edition (BSID-3)</td>
<td>✓</td>
</tr>
<tr>
<td>Griffiths Mental Development Scales (GMDS)</td>
<td>✓</td>
</tr>
<tr>
<td>Leiter International Performance Scale –R²</td>
<td>×</td>
</tr>
<tr>
<td>Merrill-Palmer-Revised Scales of Development (MP)</td>
<td>✓</td>
</tr>
<tr>
<td>Mullen Scales of Early Learning (MSEL)</td>
<td>✓</td>
</tr>
<tr>
<td>Psychoeducational Profile-3 (PEP-3)</td>
<td>✓</td>
</tr>
<tr>
<td>Stanford-Binet Intelligence Scales- Fifth Edition (SB-5)</td>
<td>✓</td>
</tr>
<tr>
<td>Wechsler Preschool and Primary Scale of Intelligence- Fourth Edition (WPPSI-4)</td>
<td>×</td>
</tr>
</tbody>
</table>

*Leiter International Performance Scale-Revised (Roid & Miller, 1997); Psychoeducational Profile- Third Edition (Schopler, Lansing, Rechler, & Marcus, 2005); and WPPSI (Wechsler, 2012) added to information from Brassard and Boehm (2007).

*Note a new edition has recently been released (2013) and this information may not apply to the new edition; ¹No discontinuation procedure, must administer all items.
A child’s chronological age may help in narrowing the choice of assessments available. However, many children with ASD function at a level significantly below their chronological age, and choosing a test that may be sensitive to their skills may be required where children have a known or suspected developmental delay or intellectual impairment. Finding a test which includes both chronological and mental age can be a challenge, and clinicians may consider whether a test that provides age equivalents may be suitable where a child’s mental age is estimated to be significantly lower than their chronological age. Although, age-equivalents require careful interpretation, they may be useful in obtaining an estimate of a child’s current ability level and may prove useful for measuring change over six-month intervals following early intervention (e.g., using the Mullen Scales as suggested by Akshoomoff, 2006)

Initial screening of a child’s verbal ability, understanding of basic concepts, and processing speed (e.g., to consider timed/non-timed tests) is recommended to inform test selection. Previous research has shown for example, that poorer verbal ability is linked to poorer outcomes on more verbally-based tests such as the SB-5 (Lennen, Lamb, Dunagan, & Hall, 2010). If an assessment contains verbal instructions, and a child does not possess the necessary level of receptive skills to understand the requirements, it will be unclear whether the child did not correctly respond due to their ability or whether they did not understand the requirement of the task. For children with limited or no verbal ability, the use of a non-verbal assessment may yield more information about the extent of a child’s abilities depending on the referral question. Additionally, screening of a child’s basic skills (e.g., pointing) and readiness for assessment (e.g., ability to sit and attend) is recommended. These skills may limit which assessments may be conducted with a child, and whether assessment should be deferred until a child has been taught the required skills to complete the specific test.

Another consideration when choosing an assessment is whether a brief assessment or a full battery of assessments is required. This may depend on the reason for referral, the child’s behaviour, and attention span. For example, a clinician may choose to administer the MSEL over the Bayley Scales of Infant Development (BSID) which can be a longer test to administer, where behaviour or attention difficulties are present. In addition, where the assessments are used for evaluation purposes, and may need to be repeated over time to identify changes or developments, the age range across the study or intervention/monitoring period may need to be considered. For example, where a child is to be assessed at five and eight years of age, the Stanford-Binet may be used at both time points, whereas using Wechsler scales this age range may necessitate using the WPPSI and then the WISC.

### Preparation for Assessment

It is recommended that the test location and time is chosen to fit with the child and family’s needs. For example, some children may respond better in their usual environment and assessment at their school or home may be more appropriate than a clinic setting. Young children in particular may respond better when a caregiver or parent is present. The assessment time should consider the child’s/school’s usual routines such as morning tea, toileting, and nap/sleep times and avoid these to maximize motivation (Akshoomoff, 2006). In our experience, it can be helpful to give families a letter to confirm their assessment day/time/location and anything they need to bring (e.g., snack, reinforcers, communication devices etc.), as well as short text message on a company telephone number to confirm the day before.

### Table 2

<table>
<thead>
<tr>
<th>Assessment Preparation Checklist</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prior to the Assessment</strong></td>
</tr>
<tr>
<td>• Avoid mealtimes and naptimes in setting assessment time/s</td>
</tr>
<tr>
<td>• Minimise any environmental distractions for the time/s of the assessment (e.g., lawn maintenance)</td>
</tr>
<tr>
<td>• Prepare visual supports for assessment where required</td>
</tr>
<tr>
<td>• Set a location, time, and date in session or telephone</td>
</tr>
<tr>
<td>• Send/give a letter to confirm the assessment in advance, include social narrative if using</td>
</tr>
<tr>
<td>• Call or text message to confirm 24 hours in advance with parents/teachers as applicable, remind to bring/send any applicable items (e.g., reinforcers)</td>
</tr>
<tr>
<td>• Check with caregivers for any recent illness or injury that may affect the assessment</td>
</tr>
<tr>
<td><strong>On the Day</strong></td>
</tr>
<tr>
<td>• Remove any potentially hazardous materials or items (e.g., small toys) from the assessment room and any potential distractions</td>
</tr>
<tr>
<td>• Make sure all materials are in the kit and that you have all relevant manuals, picture books and other materials (e.g., toys) that will be needed during the assessment</td>
</tr>
<tr>
<td>• Put a visual cue for the assessment on child’s visual schedule (if using)</td>
</tr>
<tr>
<td>• Collect any items for child’s assessment that caregivers have arranged (e.g., reinforcers, drinks, snacks, and/or communication device/s)</td>
</tr>
<tr>
<td>• Complete front page of record form e.g., date, date of birth, and arrange stationery (e.g., pencils, erasers, spare paper for notes etc)</td>
</tr>
<tr>
<td>• Find basal item (if applicable) and arrange test materials in room and prepare any materials in advance (e.g., for the first item)</td>
</tr>
<tr>
<td>• If using, arrange reinforcer box, finish box and any visuals (e.g. first/then, schedules) to be used to facilitate the process</td>
</tr>
<tr>
<td>• Consider furniture and seating placement and arrange as necessary (e.g., table against wall)</td>
</tr>
<tr>
<td>• Put sign on door to “not disturb” if testing in a clinic or school</td>
</tr>
<tr>
<td>• Set up video equipment if using</td>
</tr>
<tr>
<td>• Check child has gone to the toilet recently/has a clean diaper before transitioning to assessment room</td>
</tr>
</tbody>
</table>
Prior to the assessment being conducted, parents/caregivers should be informed of the purpose of the assessment, costs, and when to expect results. Clinicians should also gather information about the child's test-taking skills (as discussed above), challenging behaviours that may impact on the assessment (e.g., non-compliance, biting of materials or people, anxiety), allergies (e.g., latex), sensory sensitivities (e.g., loud noises; air-conditioning), response to changes in routine or environment, use of visuals and communication devices, and preferred activities and interests. This information and preparation supports the clinician to obtain the most valid and safe assessment. For example, it may be decided in advance to remove or reduce the use of small items that may present a choking hazard for a child who tends to mouth or bite items. Where allergies are present, caution around these materials and items in the test location may be needed (e.g., use of gloves, no nuts for lunches, etc.). Some children may benefit from a social narrative (for more information see Wong et al., 2014) to explain and understand the social situation of the test to reduce anxiety and predictability for a child who prefers routine and may have difficulty with the unfamiliar test situation. Knowledge of a child's preferred activities and interests can be used to select appropriate materials for the breaks and reinforcers to maintain children's interest and attention (for more information on reinforcement and ASD see Wong, et al., 2014). Common reinforcers in our practice include favourite foods or snack, "high fives", tickles, puzzle play, cause and effect toys, books (e.g., "Thomas the Tank Engine"), and short periods of non-destructive self-stimulatory behaviour (e.g., lining up objects). The use of a visual work schedule of tasks may also be of assistance to some children with ASD, and ideally would need preparing in advance using photographs or pictures of test items or activities (for further discussion see Klinger, O'Kelley, & Museey, 2009). A checklist to assist with preparation on the day, based on our clinical experience and the above recommendations, can be seen in Table 2.

### Strategies for Maintaining Engagement during the Assessment

Maintaining children's engagement and reducing off-task and challenging behaviours may be particularly important for assessing children with ASD. Thus, without affecting standardised procedures, it is important to enhance engagement with children with ASD as much as possible, as motivation and attention in children with ASD has been shown to considerably affect test performance and outcome (e.g., Koegel, Koegel, & Smith, 1997). One element of this is planning in advance as discussed above. The second element is during the assessment, and may include managing challenging behaviour, using reinforcement procedures, administration in short chunks of time; predictable breaks contingent with on-task performance; allowing parents to attend; and allowing the child to complete the assessment on the floor (Akshoomoff, 2006; Koegel, et al., 1997). In addition, it can be helpful to allow children a short period of play (10-15 minutes) to warm up to the examiner and test situation prior to assessment while making observations (e.g., language sample) during this time; having children assist in packing up test items (to give them something to do while setting up the next task); placing completed items in a "finish box" to show they are completed; preparing the test materials in advance to allow faster transition between items to keep the assessment more engaging; and alternating desirable/less desirable tasks where flexible administration is allowable in the assessment (e.g., MSEL, PEP-3).

It is important to be aware of what can and cannot be scored (i.e. allowable modifications) and to ask parents (if present) whether a child can complete tasks they may refuse or not demonstrate. Often, as also observed by Akshoomoff (2006), parents will report children cannot demonstrate a skill under the constraints of the task (e.g., “Point to the red crayon" parents will say can respond to "Give me"). In this case it is recommended to administer the item as intended for scoring purposes but to note, or test, these adaptations after the standard administration (but score as 0 or failing), for informational purposes. The specific strategies and adaptations used to gain/maintain attention and their success should also be recorded and discussed in the behavioural observations section of the report or during feedback as applicable. We have also found, like Akshomoff (2006), that it can be useful to discuss with parents, whether they felt the skills their child showed were representative of their usual functioning, particularly if difficulties with gaining/maintaining attention and engagement are observed. The Communication and Symbolic Behavior Scales Developmental Profile (Wetherby & Prizant, 2002) provides an excellent example for such a discussion that includes a parent questionnaire for completion at the end of the assessment that asks whether the child's presentation (e.g., play, communication, alertness) was typical or better/worse than usual.

### Conclusion and Recommended Reading

To ensure the best opportunity for a valid assessment, consideration of an individual child with ASD's unique strengths and needs is important to facilitate assessment of their cognitive or developmental skills. Considerations may include features of the diagnosis such as communication impairments, and associated features such as challenging behaviour. This information can assist in assessment selection, advance preparation, and selection of strategies to maintain engagement during the assessment. Valid assessment is important for treatment planning, evaluation of progress, and assessing eligibility for additional supports or funding. For further information on assessment of children with ASD including psychoeducation for parents around assessment, interpretation, report-writing and feedback which were beyond the scope of this article, please see below for a list of recommended reading.

For sharing with parents/caregivers:

For clinicians:


References


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Austism and Education in Australia

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Abstract

The proportion of school-aged children diagnosed with autism (ASD) in Australia is increasing. Most attend a regular school and most experience some restrictions and difficulties. There is a range of issues for these students including, poor academic performance relative to their cognitive ability, bullying, high rates of co-morbid mental health problems, suspension and exclusion and poor post-school outcomes. Key characteristics of autism, particularly social communication, make school challenging for students with autism and in turn make students with autism challenging for schools. However schools can and do succeed in including students with autism. Good practice in autism education involves: individualised programs based on strengths, managing the environment to facilitate participation and engagement, curriculum adaptions and adjustments, focus on managing the hidden curriculum, a collaborative, multidisciplinary team approach, provision of structure and routine, evidence supported strategies, data collection and review. Schools in Australia are largely failing these students. Clear focus and direction and resources at a systems level are required to improve educational outcomes for this population.

Increasing numbers of children in Australia are being diagnosed with autism (ASD). Debate continues about the best educational placement for these children and states vary in the types of educational placements available. For many professionals, inclusion in mainstream education is the goal for most, if not all children with autism. According to the Australian Bureau of Statistics in Australia the majority (95%) of children and young people with autism in Australia are enrolled in a school. Of this majority, 56% attend a mainstream school and 44% attend a special school or a special class in a mainstream school. Of those enrolled in school some (6%) were reported to be unable to attend school at all because of their disability, and of those that did attend school 86% reported ‘having difficulty’ at school which usually involved difficulties fitting in socially, communication, and learning. Only a tiny percentage of children with autism attended school and did not experience any educational restrictions (ABS, 2012).

What are the issues?

Poor academic performance

Students with autism under-perform academically relative to their level of cognitive ability (Ashburner, Ziviani & Rodger, 2010). This Australian study found that 54% of students with autism and without intellectual disability, were rated by their teachers as underperforming relative to 8% typically developing peers, despite supports provided for students with autism in classrooms. Teacher judgment of academic performance has been shown to be highly accurate with high correlations with standardised tests of academic performance (Gresham & Kendall, 1987). Academic expectations of students with autism are likely to be high as a result of their, often exceptional, cognitive abilities. The majority of students with autism in mainstream schools test in the average IQ range or above, yet have cognitive characteristics (e.g., weak central coherence, planning difficulties) which make academic success difficult. In addition, despite fluent expressive language and extensive vocabularies, social communication difficulties result in social isolation, anxiety and depression (Brewin, Renwick & Schormans, 2008) and poor academic outcomes.

Bullying

We know students with autism are more likely to be the targets of bullying in special education settings (van Roekel, Scholte & Didden, 2010). In mainstream settings in the US, up to 75% of students with autism experiencing bullying at school, four times more than the non-disabled population (Little, 2001). Bullying victimisation is associated with negative outcomes. Children who experience high levels of bullying (once or more per week) tend to exhibit higher levels of anxiety, hyperactivity, self-injurious behaviours, stereotypic behaviours, and elevated emotional sensitivity (Cappadocia, Weiss & Pepler, 2012). Victimisation is associated with academic difficulties and school avoidance, as well as internalizing mental health problems such as anxiety, depression, and suicidal ideation (Schroeder, 2014).
Depression, anxiety and other co-morbid mental health conditions

Problems include sleep disturbance and irritability, pica and eating disorders, and ADHD (Williams & Roberts, in press). Students with autism in schools are more likely than the typical population to have mental health problems including mood and anxiety disorders. Long term (6 years post-diagnosis) follow up data compared mental health outcomes for 59 cognitively able children with autism with the typical population (Kim, Szatmari, Bryson, Steiner & Wilson, 2000). A higher rate of anxiety and depression problems was associated with autism, which in turn had a significant impact on the children's overall adaptation. Students with autism in mainstream classes were rated by their teachers as having poor emotional and behavioural regulation compared to age- and gender-matched typically developing students and significantly higher rates of behavioural and emotional difficulties (including attention difficulties, anxiety, depression, oppositional and aggressive behaviours (Ashburner et al., 2010)). Frequent victimisation is one factor related to internalising mental health problems (Zablotsky, Bradshaw, Anderson & Law, 2013).

Anxiety is a common problem in people with autism and in many this develops into an anxiety disorder such as specific phobia, panic disorder, separation anxiety disorder, social anxiety disorder, generalised anxiety disorder or obsessive compulsive disorder. Estimates vary: Muris et al. (1998) found that 84% of children with pervasive developmental disorder met the full criteria of at least one anxiety disorder while Howlin and Moss (2012) found that almost 30% of children aged 10 to 14 years with autism suffered from social anxiety disorders.

Participation and Quality of Life in relation to school and school experience

School is likely to be an unhappy experience for the child with autism and their family (Brewin et al., 2008). Parents may be concerned that their child's disability was frequently unrecognized, misunderstood and underestimated. They may be concerned about the lack of understanding, education and training of staff in the field of autism, which can result in a lack of flexibility. Schools may fail to recognise the particular interests and skills of their children and place value on activities such as team sports, which students with autism typically find incomprehensible or unrewarding. When students with autism attend mainstream schools they may spend as much as two thirds of their time withdrawn from the classroom, (Newman, 2007) and when they are in mainstream classrooms, teachers report they participate less actively than their typical peers. Academic participation is a significant factor in predicting participation in post-secondary education (Chiang, Cheung, Hickson, Xiang, & Tsai, 2012).

School attendance, suspension and exclusion

Students with ASD are more likely to be suspended from school compared to other disability groups or typical peers (Barnard, Prior & Potter, 2000). A government committee, set up in the UK to investigate the issues for students with social and emotional needs in schools (House of Commons Education and Skills Committee, 2006), found that the clear majority of permanent exclusions (87% in primary and 60% in secondary schools) related to pupils with social and emotional needs (SEN) and that pupils with autistic behaviour made up a significant proportion of this group. Exclusion was a greater problem for the most cognitively able children with 29% of 'very high functioning' children experiencing exclusion from school. Reasons given for exclusion included teacher inability to cope, student inability to cope, lack of staff/resources/training, and problem behaviours ranging from disruption to violence and aggression.

Information about the numbers of students with autism excluded from school in Australia is scarce. In a small study of children with autism in NSW schools, 40% failed in their initial school placement within 12 months and had to change schools, usually from a mainstream class to a disability specific placement (Lilley, 2014).

Post-school outcomes

When compared to people with other disabilities, people with ASD experience poorer post-school outcomes. The Australian Bureau of Statistics (ABS) Survey of Disability Ageing and Carers (2012) reported that 81% of people with autism who had finished school had not completed a post-school qualification, well above the rate for both the rest of the population with disability and people with no disability. When compared to people with other disabilities, people with ASD experience poorer outcomes in relation to workforce participation, 34% compared to 54% labour force participation rate for people with disabilities and 83% for people without disabilities (ABS, 2012).

While failure to complete post-school qualifications and find employment cannot be attributed to the education system alone, school systems should accept some of the responsibility for the poor post-school outcomes of students with autism.

Square pegs in round holes? Why are schools and students with autism incompatible?

The core characteristics of autism, which are present from an early age and continue for life, present major barriers to participation in education for students and significant challenges for those teaching them. These characteristics include:

- Difficulty relating to others and poor functional communication, different ways of communicating and different motivation to communicate (e.g., difficulty in identifying a topic of interest to others, extensive vocabulary, but not appropriate to social context).
- Obsessive insistence on environmental sameness and powerful interests. These differences and difficulties result in internalised responses (such as self-stimulatory and self-injurious behaviours) or externalised responses (such as aggression towards others) (American Psychiatric Association, 2000). Irregular patterns of processing sensory information including hyper- and hypo-sensory sensitivities and distortions.

- Irregular patterns of cognitive and educational strengths and deficits, including splinter skills and isolated discontinuous abilities (Jordan, 1999), attentional differences such as difficulty selectively attending and different ways of learning and remembering (Ricketts, Jones, Happé, & Charman, 2013). A characteristic profile of reading performance including strengths in the mechanics of reading (i.e. word decoding) and difficulties in reading comprehension (Chiang & Lin, 2007) resulting in difficulty following and mastering the school curriculum.

These characteristics are interrelated. For example social communication impairment is a significant predictor of reading comprehension, which was found to have more impact on literacy than word recognition and oral language deficits (Ricketts et al., 2013). Motivation is particularly important for students with autism and unsurprisingly students with ASD perform best when material is relevant to them. Interestingly students with autism have the highest in Science Technology Engineering Mathematics (STEM) enrolments of all disability groups.

Students with autism challenge schools. Deficits in theory of mind abilities are a core feature of ASD (Baron-Cohen, Leslie, & Frith, 1985) and make it difficult for those with ASD to understand social cues and monitor feedback from others about how their behaviour is being perceived. This in turn increases the likelihood of marginalisation and conflict within staff and peer relationships. Problem behaviours demonstrated by children with ASD—such as emotional outbursts, tantrums, aggression and non-compliance—create substantial obstacles for school staff (Strain, Wilson & Dunlap, 2011). Difficulties with emotion regulation are likely to result in strong emotional and/or behavioural reactions (e.g., visible anxiety or crying) during interactions with staff and peers, which is likely to increase the risk of victimisation in the future, as these reactions have been found to encourage the perpetrator (Gray, 2004). Difficulties with communication may increase the risk of victimisation for individuals with ASD because assertiveness and effective communication are protective factors for coping during bullying situations (Haq & Le Couteur, 2004). In addition, restricted interests and stereotyped behaviours that characterise ASD are likely to be perceived by staff and peers as being odd or different, resulting in an increased risk of being marginalised within the peer group and targeted by aggressive peers (Dunn, Saiter & Rinner, 2002).

Students with autism are difficult for staff to relate to intuitively (Jordan, 1999). Both staff and students with autism have to work cognitively at overcoming these failures of empathy. In addition, staff in schools do not feel supported because there are few models and procedures to facilitate the successful inclusion of these students, meaning staff are faced with the task of designing programs in the absence of clear guidelines and procedural protocols (Simpson, de Boer-Ott, & Smith Myles, 2003). Many otherwise skilled and competent regular educators report that they consider themselves to be less than fully capable of serving the needs of students diagnosed with autism (Simpson, 1995), and ill equipped to meet their social, learning, and behavioural needs (Marks et al., 2003).

**What makes school work for children and young people with autism?**

Interventions based on learning (also referred to as *behavioural interventions*) are demonstrated to be the most effective for children and young people with autism, not solely access to the academic curriculum, but learning based interventions to address specific characteristics of autism and improve overall quality of life (Jordan, Jones & Murray, 1998). The heterogeneous nature of autism means no one program, support, or service will meet the needs of the autistic population as a whole. Each student with autism has a unique constellation of strengths and needs. An individualised program with both academic and hidden curriculum (Smith-Myles, Trautman, & Schelvan, 2004) goals is essential to meet their communication, social and adaptive behaviour needs and facilitate participation in school both in and out of the classroom. They require social, communication and adaptive behaviour support to make a successful transition to tertiary education, training or employment (Department of Education & Science, 2006). Some will only require minimal or moderate modifications to the general education curriculum, whereas others may need major adaptations and a functional academic approach (Ivannone, 2003).

Successful educational programs for students with autism share many, if not all, of the following characteristics:

**Individualised approach and program**

Comprehensive identification and assessment of the unique combination of characteristics is required for each student to enable relevant individualised planning and instructional support. Each student’s program will address their unique preferences, interests, behavioural presentations, and learning style with relevant goals and strategies to ensure they experience educational success (Ivannone, 2003).

**Focus on strengths-based engagement**

Engagement refers to the amount of time that the student is attending to and actively interacting in his or her social and nonsocial environments. Engagement and participation are critical to success at school and have been cited as one of the best predictors of positive student outcomes (Rogers, 1999). Engagement of students with ASD will be unlikely unless there

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6 All students have to deal with the ‘hidden curriculum’. This refers to unspoken cultural and social information and rules governing the social aspects of school life and adolescence, dictates how students should interact with peers, teachers and other adults and what ideas and behaviours are considered acceptable or unacceptable.
is some deliberate instructional program design incorporating preferred materials and activities, and capitalising on a student’s interests and preferences (Hurth, Shaw, Izeman, Whaley & Rogers, 1999) and focus on strengths and weaknesses to determine the most appropriate supports and intensity to meet individual goals (National Research Council, 2001).

Ecological management
In addition to developing a program for the student to facilitate skill acquisition, we need to consider ways in which we can adapt the environment to make it more comprehensible and manageable for students with autism. This involves managing the physical and the social environment to minimise factors that are disruptive or disturbing to the student. To do this, attitudinal and social as well as physical supports are essential, including the management of change and facilitating transitions. Attitudes across the school community towards inclusion of students with autism in regular classroom have a direct impact on the success of placements for students with autism (Simpson, et al., 2003). Leadership, a positive attitude, shared ownership and flexibility on the part of the whole school community are key to successful inclusion.

Multidisciplinary
Students with autism typically have complex needs across many domains—communication, speech-language, motor, sensory, behavioural and academic—and require multidisciplinary team input in a comprehensive program planning and implementation process. Multidisciplinary input is also required to work with classmates and the whole school community to develop the communication and social skills required to understand and support students with autism (Simpson, et al., 2003).

Functional Positive Behaviour Support (PBS)
PBS is a well-established, effective framework that involves functional assessment based on understanding the purpose of, and environmental triggers for, a specified problem behaviour in order to identify variables that reliably predict and maintain problem behaviours (Horner & Carr, 1997). Functional behaviour assessment (FBA) using data gathered through indirect measures (e.g., interviews) and direct measures (e.g., observations of antecedents, behaviours, and consequences) is used to develop individualised support plans. The primary goal of PBS is to enhance the individual’s quality of life by expanding his or her existing behaviours and adjusting the learning environment. The secondary goal is to make problem behaviour ineffective, inefficient, and irrelevant (Carr et al., 1999).

Systematic instruction, structure, routine, visual supports
Systematic instruction involves carefully planning for instruction by identifying goals, outlining procedures for teaching, implementation, evaluation of effectiveness, and adjusting instruction based on data (Wrestling & Fox, 2000). Students with autism do better in classrooms and programs that are structured and predictable (Olley & Reeve, 1997) and where the curriculum (activities, schedule, environment) is clear (i.e., comprehensible) to both the students and educators. Systematic instruction also provides a structured teaching plan for transition, generalisation and maintenance of learned skills. Students with autism typically have better visual than auditory processing, poor comprehension skills and poor organisational abilities. As a result students with autism respond best when information is presented visually as well as aurally (Rogers, 2013).

Collaborative family involvement and support
Programs should be implemented consistently across home school and community environments to have maximum effect. Involving the family is the best way to achieve this. In the US, family involvement in the individual planning process is mandated. This is not the case in Australia. However, good practice in autism education emphasises the importance of considering family preferences and knowledge of the child when determining the goals to be taught and the methods by which instruction will be delivered (Iovannone, 2003). A collaborative partnership with the family can contribute to the effectiveness of interventions and programming, particularly when the strategies are used in multiple environments.

Academic curriculum adaptations and adjustments
Curricular modifications, general education classroom support and instructional methods underpin all placements of students with special needs in classrooms (Simpson, et al., 2003). In Australia, instructional adjustments proscribed by the Australian Curriculum Assessment and Reporting Authority (ACARA) which are relevant for students with autism include:
- provision of alternative representations of teaching and learning materials (e.g., visual representation) and explicit, systematic instruction;
- motivating students through engagement with personal interests;
- organising and connecting knowledge, skills and values to promote generalisation, and
- using naturally occurring learning opportunities to enhance individual learning goals (ACARA, 2013).

Specific curriculum content for students with autism
Communication and social interaction problems are core deficits in individuals with ASD. Children with autism display particular difficulties in the development of social reciprocity. Specialised curriculum should include systematic instruction in social engagement skills, including initiating and responding to social bids, appropriate recreational or leisure skills, and language comprehension and communication. In addition, educators should consider the functionality of the skills targeted within the curriculum. Focus should be on those skills that (a) are most likely to be useful in the student’s life to control his or her environment, (b) will increase the student’s independence and quality of life, and (c) will increase the student’s competent performance (Dunlap & Robbins, 1991).

Data-based evaluation and review
Comprehensive evaluation should include evaluation of the provision of services and supports, evidence of benefit from participation and education, evidence of facilitation of membership in class/school and demonstration of appropriate participation (Simpson, et al., 2003).
In summary, educational programs for students with autism are most effective when they are developed by a multidisciplinary team working closely with parents and other key people in the child's life. Effective programs are based on the strengths and needs of the individual and take into account the priorities of families and resources available in their environment. Programs should support the participation of students with autism in both academic and non-academic activities at school, include strategies to maintain and generalise mastered skills and facilitate independence. Effective programs will be evidence-based, functional, holistic, and motivating for students, will reflect the student voice and be developed with respect.

Support for school communities
Tobias (2009) noted that teachers require knowledge about the nature of ASD in order to understand and to interpret students' behaviour correctly, as well as needing to acquire the skills needed to deal with complex issues that may arise. Children with ASD require more specialised teaching techniques than those typically included in general teacher education and specialist training in special education needs (National Autistic Society 2006). Recent evidence suggests that teacher knowledge of specialist, individualised approaches to teaching children with ASD is one of the keys to successful inclusion (Keane, Aldridge, Costley & Clark, 2012).

Building capacity in schools to improve educational outcomes for students with autism
Examples of effective strategies at a whole school level include; reduced class sizes, provision of adequate teacher planning time, appropriately trained support personnel and provision of relevant staff professional development. The leadership, vision and capacity of the school principal to support the inclusion of students with disability including autism, is critical and principals need to be supported by the educational system. Despite recent renewed emphasis on the implementation of the Disability Standards in schools nationally, outcomes for this population continue to be poor compared to both typical and non-typical peers. A targeted, consistent, autism-specific approach based on school leadership and capacity building at a national and a state level is required to improve educational outcomes for this population to enable young people with autism to participate and contribute.

References


The Secret Agent Society Social-Emotional Skills Training Program for Children with Autism Spectrum Disorders

Renee Beaumont, PhD

Program Overview

Secret Agent Society (SAS) is a group-based multimedia social skills program that was originally developed for 8 to 12-year-old children with high-functioning autism spectrum disorders (ASD; Beaumont, 2008). The program consists of small group ‘club meetings’ for children, parent and teacher information sessions and resources, real-life practice missions, visual supports and a system to monitor and reward skill development at home and at school. The intervention can be delivered over 12 or 24 sessions in a private practice, community or school setting.

The SAS computer game and other fun espionage-themed activities are used to teach children how to recognise emotions in themselves and others, express their feelings in appropriate ways, talk and play with others, cope with mistakes and transitions, and prevent and manage bullying and teasing. Activities include the Helpful Thought Missile Game (shooting down unhelpful enemy thoughts with helpful thought missiles), the Secret Message Transmission Device walkie-talkie game (practising detecting how other people feel from their tone of voice) and the Challenger Board Game (a role-play based game to practise the social-emotional skills taught in the program).

Children self-evaluate their success at practising learnt skills at home and at school in a computerised Secret Agent Journal. A scene generator device can be used to visually illustrate how skills were applied, optimally engaging and supporting children who are visual learners and those with writing difficulties. Reproducible assessment measures with demonstrated reliability and validity are also included to evaluate children’s social-emotional skill profile and to track their progress through the program.

SAS has achieved both local and international acclaim. In 2014 alone, it was awarded the Autism Spectrum Australia National Advancement Award and the US Teacher’s Choice Learning Magazine Award for the Family (SAS Family Kit). The program is distributed by the Australian Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), and to date, over 700 professionals in nine countries worldwide have been trained to deliver the intervention.

Theoretical Foundations

SAS is grounded in several different theoretical frameworks of ASD, in addition to drawing on the broader child therapy and developmental psychology literature. Specifically, SAS teaches children how to detect the thoughts and feelings of themselves and others, addressing theory of mind or perspective-taking difficulties that are purported to underlie many of the social challenges faced by individuals on the spectrum (Hoogenhout & Malcolm-Smith, 2014). The intervention also upskills children to integrate relevant contextual, verbal and nonverbal clues to accurately interpret social situations – targeting weak central coherence difficulties (i.e. problems with focusing on irrelevant details and failing to see the ‘big picture’ (Pellicano, Maybery, Durkin & Maley, 2006)). Computerised ‘choose your own adventure’-style, virtual reality missions and a step-by-step problem-solving formula (D.E.C.O.D.E.R) are used to address executive functioning difficulties with planning and set-shifting. These program components help children to think more flexibly about different solutions to social problems, rather than perseverating on unsuccessful coping strategies such as physical retaliation, escape or avoidance behaviours.

SAS also draws on principles of applied behaviour analysis (Matson, et al., 2012), with complex social skills broken down into component steps, and behavioural antecedents and consequences analysed and modified to bring about positive change in children’s behaviour. For example, a structured Home-School Diary is used to monitor children’s skill usage on a daily basis at home and at school, with rewards provided in exchange for points earned. The program teaches cognitive-
behavioural therapy strategies for coping with unpleasant feelings (e.g., using relaxation ‘gadgets’ to feel happier, calmer and braver), and recent research trials have included supplementary acceptance and commitment therapy activities (cognitive defusion and mindfulness) for children who are reluctant to challenge unhelpful thoughts or struggle to tolerate uncomfortable emotions. Typical child development literature informed the development of age-appropriate step-by-step guidelines for the social skills taught in the intervention (e.g., the steps for talking and playing with others).

The Evidence Base

Results from the initial randomised controlled trial of the SAS Program (formerly called the Junior Detective Training Program) indicated that 76% of children with Asperger syndrome who showed clinically significant impairments in their social skills on a parent-report measure at pre-intervention, improved to within the range of typically developing children after receiving the program or by five months follow-up. Improvements in children’s social-emotional functioning were shown on child, parent and teacher report measures and across both home and school environments (Beaumont & Sofronoff, 2008).

A subsequent mainstream school repeated-measures evaluation of a variant of the SAS group program suggested that the intervention was effective in improving the social-emotional skills and behaviour of 8 to 12 year-old students with ASD at both home and school (Beaumont, Rotolone & Sofronoff, in press). In addition, an independent between- and within-groups evaluation in Autism Spectrum Australia (Aspect) specialist classes for students with ASD showed program improvements were maintained at 12 months follow-up on all outcome measures (Einfeld et al., in preparation). The latter trial also showed that the improvements in social-emotional functioning made by students over the SAS intervention period were significantly greater than those achieved over a longer period where students received their standard school social-emotional curriculum and that these were unrelated to children’s gender, age (8 to 14 years), IQ, verbal comprehension level or socio-economic status (Einfeld et al., in preparation).

A pilot repeated-measures study of the SAS Program with children who have social-emotional challenges but without an ASD diagnosis showed comparable treatment effects to those achieved with children who have ASD (Pearson, 2014). Positive findings have also been demonstrated in studies using baseline-comparison phases for Skype-assisted parent delivery (Sofronoff, Silva, & Beaumont, in press) and face-to-face individual variants (Tan, Mazzucchelli, & Beaumont, 2014) of the intervention.

A randomised controlled trial of a light-touch tele-health delivery variant of the program is currently in progress in Queensland, New South Wales and Victoria, Australia. An additional randomised controlled trial evaluating the effectiveness of an SAS program variant for youth with Autism Spectrum Disorders and one or more comorbid anxiety, depression, ADHD or disruptive behavioural disorder diagnoses is also underway at York University, Canada. Early findings of the latter trial are showing positive outcomes for children and families, both in terms of improvements in children’s social functioning and affiliated mental health symptomatology.

Professional Training Course

To deliver the group SAS Program, professionals are required to attend a two-day practitioner training course. These active skills training courses are run throughout Australia and involve a mix of didactic presentations, analysis and critique of filmed session footage, small and large group activities and opportunities to practise delivering program content with professional guidance and support provided by the course facilitator. Individual follow-up by phone or Skype supervision is provided to help professionals optimally tailor the program to meet the needs of their clients and workplace. For those professionals wanting to integrate the SAS software into the existing work they do with children and families (rather than running the entire group intervention), a one-day Computer Game Workshop is also being offered throughout Australia in 2015. An optional accreditation process is also available to recognise competence in program delivery and to allow professionals to take on a regional advisor role.

Next Steps

A randomised controlled trial of the SAS group program is scheduled to commence in the USA later this year with children who have an anxiety or disruptive behavioural disorder diagnosis without comorbid ASD. Future program updates and research will focus on further technological enhancements to the intervention and practitioner training model. These include the proposed development of an app to provide additional support for children’s skill generalisation and exploring the utility and effectiveness of alternative modes of delivering practitioner training (e.g. webinars and online training). Development of whole-of-class and teen and adult variants of the program are also currently underway, and are scheduled to be evaluated as strategic projects within the Autism CRC.

For further information about the program or practitioner training courses that are being offered throughout Australia, please go to www.sst-institute.net

References


PhD Spotlight

High-functioning Autism Spectrum Disorders in Adulthood: Investigating Factors that Influence Psychosocial Outcomes

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Abstract

High functioning autism spectrum disorders (HFASD) is a chronic neurodevelopmental disorder characterised by deficits in social interaction, communication difficulties, sensory impairments and atypical behaviour (Attwood, 2007; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001; Kasari & Rotheram-Fuller, 2005; Martin & McDonald, 2004). Autistic Spectrum Disorders (ASD) has an estimated prevalence in Australia of 6.3 per 1,000 individuals, affecting approximately half a million families (MacDermott, Williams, Ridley, Glasson, & Wray, 2007). However, there is a dearth of empirical research investigating the psychosocial outcomes for adults with HFASD.

This small body of literature suggests that psychosocial outcomes for adults with HFASD are poor to moderate at best. The majority of individuals report persisting social impairments, poor occupational achievement, high dependence on others and a lack of partner relations. In addition, cognitive (i.e., IQ and executive function tasks) and linguistic ability (i.e., verbal IQ, tests of reading and comprehension) have consistently predicted positive outcomes in adulthood (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Engstrom, Ekstrom, & Emilsson, 2003; Howlin, Goode, Hutton, & Rutter, 2004; Jennes-Coussens, Magill-Evans, & Koning, 2006; Larson & Mouridsen, 1997; Renty & Roevers, 2006; Szatmari, Bartolucci, Bremner, Bond, & Rich, 1989; Venter, Lord, & Schopler, 1992; see Appendix A for a summary of these articles).

Due to the multidimensional nature and complex symptomatology of ASD, no one theory comprehensively explains the full characteristics of the disorder. However, three dominant cognitive explanations include: (1) The Theory of Mind hypothesis that is, the inability to account for the mental states of others (Baron-Cohen, Leslie, & Frith, 1985; Baron-Cohen, Richler, Bisarya, Gurunathan, & Wheelwright, 2003; Baron-Cohen, et al., 2001); 2) executive dysfunction – that is, being driven by a need for sameness; problems with switching attention; a tendency to perseverate; and difficulties with impulse control (Ambert, Russell, Perry, Morris, & Murphy, 2006; Hill & Bird, 2006; Ozonoff, 1998; Ozonoff, Pennington, & Rogers, 1991); 3) weak central coherence – that is, difficulties perceiving the overall meaning or gist in a given situation (Frith & Frith, 2003; Frith & Happé, 1994; Happé, 1999). Each of these explanations can help to account for the different primary and secondary symptoms of HFASD and have been extensively researched in clinical populations, particularly with children and adolescents (Castell, Frith, Frith, 2002; Pernfr, Frith, Leslie, & Leekam, 1989; Szatmari, Tuff, Finlayson, & Bartolucci, 1990).

Numerous studies have documented the comorbidity of HFASD with both physical and psychiatric disorders (Cederlund et al., 2008; Gillberg & Cederlund, 2005; Reiersen, Constantino, Volk, & Todd, 2007). For adolescents with HFASD, research has shown that they perceive themselves differently, report lower self-esteem and have poorer psychological outcomes than typically developing peers (Capps, Sigman, & Yirmiya, 1995; Lee & Hobson, 1998; Vickerstaff, Heriot, Wong, Lopes, & Dossetor, 2007; Williamson, 1990).

Study Overview

High-functioning autism spectrum disorders (HFASD) is a chronic neurodevelopmental disorder largely characterised by deficits in social interaction, communication difficulties, sensory impairments and atypical behaviour (Attwood, 2007; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001; Kasari & Rotheram-Fuller, 2005; Martin & McDonald, 2004). Autistic Spectrum Disorders (ASD) has an estimated prevalence in Australia of 6.3 per 1,000 individuals, affecting approximately half a million families (MacDermott, Williams, Ridley, Glasson, & Wray, 2007). However, there is a dearth of empirical research investigating the psychosocial outcomes for adults with HFASD.
Craig, & Slinger, 2008). Children with HFASD are likely to demonstrate patterns of emotion dysregulation and adopt fewer adaptive coping mechanisms when compared to neurotypical children (Konstantareas & Stewart, 2006; Rieffe et al., 2011). Research has also indicated a clear neurocognitive influence whereby individuals with HFASD are significantly impaired on executive function tasks, particularly those that target response initiation and intentionality (Hill & Bird, 2006; Pennington & Ozonoff, 1996).

Despite extensive research on the aetiology and sequelae of HFASD, there is a paucity of empirical studies that have investigated the role of executive dysfunction in the core impairments of HFASD (i.e., social, communicative and sensory impairments and atypical behaviours). Furthermore, there are a limited number of studies investigating the stress-buffering role of psychological resources, such as self-perceptions (i.e., health-related cognitions, self-concept and perceived social support), emotion regulation and coping strategies for adults with HFASD (Khanna, Jarwala-Parikh, West-Strum, & Mahabaleshwarkar, 2014; Renty & Roeyers, 2007). The stress-buffering model has been proposed to explain the mechanisms affecting health outcomes when individuals experience stress (Cohen, 1988; Cohen & Wills, 1985; Wheaton, 1985). Specifically, this model asserts that during a stressful event an individual's health or wellbeing is buffered by perceived psychological and physical resources (i.e., social support). There is considerable evidence that perceived availability of psychological resources moderates and/or mediates the influence of stress on health outcomes in a range of clinical settings (Berkman & Styme, 1979; Cohen, Merrelstein, Kamarck, & Hoberman, 1985; Evers et al., 2001; McCracken, 2005; Payne et al., 2012; Rosengren, Orth-Gomer, Wedel, & Wilhelmsen, 1993; Steptoe, 2000).

Applying the stress-buffering model in the context of HFASD, symptom severity (i.e., social, communicative and sensory impairments and atypical behaviours) could be conceptualised as the stressor experienced by these individuals. When managing these symptoms, the individual's psychological resources (e.g., self-perceptions [i.e., health-related cognitions, self-concept and perceived availability of social support], emotion regulation and coping strategies) may moderate and/or mediate the relationship between symptom severity and psychosocial outcomes. Thus, although high levels of symptom severity would be expected to relate to poorer psychosocial outcomes, engaging psychological resources to manage these symptoms may have a stress reducing or buffering effect on wellbeing.

In summary, adults with HFASD are often confronted by various stressors associated with their disorder (Attwood, 2007) and are faced with numerous situations that require both the regulation of emotions and employment of adaptive coping strategies (Baron, Groden, & Groden, 2006; Myles, 2003). As such, it is broadly hypothesised that self-perceptions, emotion regulation and coping styles would impact their psychosocial wellbeing. Such research would help to provide a clearer understanding of HFASD symptomatology in adulthood and clarify the role of self-perceptions, emotion regulation and coping strategies on health and wellbeing. Moreover, this research could guide the focus of tailored and potentially more effective psychological interventions.

Aims

The aims of the present project are threefold:

1. Investigate the relationship between HFASD symptom severity and psychosocial functioning (i.e., social and mental health functioning) of adults with HFASD;
2. Elucidate the associations between HFASD symptomatology, neuropsychological functioning, health-related cognitions, emotion regulation, coping strategies and psychosocial outcomes;
3. Develop and test an explanatory model of psychosocial functioning for adults with HFASD.

Design

The proposed project will be divided into three studies (see Appendix B for a diagram of the proposed structures). Study One will employ a matched control design with HFASD participants matched on gender, age and estimated IQ and will compare their functioning on measures of psychosocial and neuropsychological functioning, self-perceptions, emotion regulation and coping strategies. Study Two will incorporate a correlational design whereby the associations between HFASD symptom severity, neuropsychological functioning, self-perceptions (i.e., health-related cognitions, self-concept and perceived availability of social support), emotion regulation, coping strategies and psychosocial variables will be investigated. Study Three will involve a large on-line survey that aims to develop and test an explanatory model of psychosocial functioning and examine the role of psychological resources (i.e., self-perceptions [health-related cognitions, self-concept, perceived availability of social support] emotion regulation and coping strategies in psychosocial wellbeing for adults with HFASD (see Appendix C for proposed hypotheses for all three studies).

Participants

Based on previous research (Ambery et al., 2006; Hill & Bird, 2006; Ritvo et al., 2011), the expected effect size for the present study ranges from $d = .57$–2.01. As such, sample sizes were determined by a priori power calculations using G*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009). With power of .80 and alpha set at .05 (one-tailed testing), power analyses indicated that sample size requirements were approximately 35 per group in the matched control study. However, due to likely attrition of participants from the present study (e.g., individuals not meeting inclusion criteria, participant withdrawal and missing data), a larger sample will be recruited. As such, 50 participants in the HFASD group (i.e., Study One and Two) and 50 participants for the matched control group (Study One only) are deemed appropriate. An additional 150 individuals with HFASD will be recruited for Study Three (i.e., $n = 200$).

Individuals with HFASD will be recruited through convenience sampling from various ASD support services or
clincs across the Brisbane metropolitan area (e.g., Asperger Services Australia and Minds and Hearts). A gender ratio of 2:4:1 (male:female; Baron-Cohen et al., 2003) is likely, thus it is estimated that approximately 35 males and 15 females will be recruited for Study One and Two. The control group (Study One only) will be recruited through convenience sampling from the Griffith University subject pool as well as the researcher's social network. To meet the desired sample size for Study Three (i.e., minimum n = 200), individuals with HFASD will be targeted through established networks and affiliated relationships with other AS and autism bodies throughout Australia and other similarly developed countries (e.g., New Zealand, United States and the United Kingdom). A gender ratio similar to that of Study One and Two is anticipated for Study Three.

**Procedure and Materials**

Approximately 50 adults with HFASD and 50 matched controls will complete a selection of self-report questionnaires as well as a brief cognitive test battery (Studies One and Two). Administration of the test battery will take place in two separate phases: 1) Self-report questionnaires will be completed either online or in hard copy format; 2) Face-to-face administration of a cognitive test battery will then be conducted. The rationale for administering the full test battery over two sessions is to reduce the burden of assessment for individuals. For Study Three, an additional 150 individuals with HFASD will complete only the first phase of the test battery as an online survey. Appendix D outlines the full test battery measures, administration methods and approximate duration of testing for all three studies.

**Independent Variables**

HFASD symptom severity will be measured using the Ritvo Autism Asperger’s Diagnostic Scale – Revised (RAADS-R; Ritvo et al., 2011) which examines the following four areas: Social Relatedness, Circumscribed Interests, Language, Sensory Motor deficits. The Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) will be administered to provide an estimate of intelligence for matching purposes.

The following tests of neuropsychological functioning will also be administered: Hayling Test (Burgess & Shallice, 1997; assesses dysexecutive difficulties in response initiation, concept formation and response suppression); Delis-Kaplan Executive Function System Sorting Test (D-KEFS; Delis, Kaplan, & Kramer, 2001) provides a standardised indication of higher-level cognitive functions; Letter Number Sequencing (LNS; Wechsler, 2008 assess working memory) and The Awareness of Social-Inference Test – Revised (TASIT-RMcDonald et al., 2006 measures social perception).

The variables that comprise psychological resources will include self-perceptions (i.e., health-related cognitions, self-concept and perceived availability of social support), emotion regulation and coping strategies. Self-perceptions will be measured using the following tests: A modified version of the Illness Cognition Questionnaire (ICQ; Evers et al., 2001; a measure of health-related cognitions); 2) Six-Factor Self-Concept Scale for Adults (SFSCS; Stake, 1994; a measure of self-concept); 3) the Interpersonal Support Evaluation List (Cohen & Hoberman, 1983; a measure of perceived social support); 4) emotional regulation will be assessed using the Emotion Regulation Questionnaire (ERQ; Gross & John, 2003); and 5) coping strategies will be measured using the Cybernetic Coping Scale (CCS; Edwards & Baglioni, 1993).

**Dependent Variables**

The measures of psychosocial outcomes will include the following: an objective outcome rating scale of social functioning based on Lotter’s (1978) social adjustment scale (range from Very Good-Very Poor); Mental Health: Depression Anxiety and Stress Scales-21 (DASS-21; Lovibond & Lovibond, 1995) and the Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1965).

**Expected Analytic Procedures**

**Study One:** Comparing psychosocial and neuropsychological functioning, self-perceptions, emotion regulation and coping strategies in adults with HFASD to matched controls: A set of multivariate analysis of variance (MANOVA) tests will be conducted to investigate the between group differences on measures of psychosocial functioning, neuropsychological functioning, self-perceptions, emotion regulation and coping strategies.

**Study Two:** Examining the associations between HFASD symptomatology, neuropsychological functioning, self-perceptions, emotion regulation, coping strategies and psychosocial outcomes: Correlation analysis will be conducted between HFASD symptom severity, neuropsychological functioning, self-perceptions (i.e., health-related cognitions, self-concept and perceived availability of social support), emotion regulation, coping strategies and psychosocial outcome variables.

**Study Three:** Proposed model of factors influencing psychosocial functioning for adults with HFASD: Mediation analyses will be conducted using the test of indirect effects and biased corrected confidence intervals (Preacher & Hayes, 2004). Moderated regression analyses will be conducted using the process macro as outlined by Hayes (2009). Together, these analyses will be applied to test a proposed model of psychosocial functioning for adults with HFASD. This model will investigate both the potential moderating role of self-perceptions (i.e., health-related cognitions, self-concept and perceived availability of social support) and the mediating functions of emotion regulation and coping strategies in the relationship between HFASD symptom severity and psychosocial outcomes. Variables included will be based on both theoretical perspectives and the results of Study One and Two.

**Ethical Considerations**

Participants will be closely monitored for signs of emotional distress during the data collection phase. Individuals that display any signs of distress will be offered immediate emotional support and debriefing and the opportunity to terminate the session. Participants will be informed of their right to decline participation in any aspect of the research as well as their right to withdraw from the study at any point without adverse effects. Fatigue will be managed by administering the self-report questionnaires and cognitive test
battery separately, thus reducing the burden of assessment. Provision will be made for breaks where necessary throughout testing.

Supervision Team

- Principle Supervisor: A/Prof Tamara Ownsworth
- Associate Supervisor: Professor. Analise O'Donovan (Clinical Psychology Advisor)
- Associate Supervisor: Professor Jacqueline Roberts (Chair of Autism Centre of Excellence – Griffith University)
- Associate Supervisor: Dr Matthew Gullo (Statistics Advisor)

References


### Appendix A: Summary of Studies Examining Psychosocial Outcomes of Adults with AS and/or HFA

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<tr>
<th>Authors</th>
<th>Study Outline &amp; Sample Characteristics</th>
<th>Assessment of Key Constructs</th>
<th>Key Findings</th>
<th>Methodological Strengths and/or Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cederlund et al. (2008)</td>
<td>Prospective follow up study comparing AS and Autism. 70 males with AS (M age 21.6 years; M IQ = 103) matched to 70 male individuals with Autism (M age 24.5 years; M IQ = 59.6) on age from a representative sample in Sweden.</td>
<td>1) Diagnostic Interview for Social and Communicative Disorders (DISCO-10; Wing, Leekam, Libby, Gould, &amp; Larcombe, 2002)  2) Wechsler Adult Intelligence Scale – Third Edition (WAIS-III; Wechsler, 2000).  3) Global Assessment of Functioning Scale (GAF; American Psychiatric Association, 1994)  4) Vineland Adaptive Behaviour Scales (VABS; Sparrow, Balla, &amp; Cicchetti, 1984)  5) A structured neuropsychiatric assessment performed by the authors  6) Outcome criteria defined as either: Good outcome (e.g., being employed or having two or more friends); Fair outcome (e.g., one of the criteria specified under good outcome); Restricted outcome (e.g., neither of the criteria specified under good outcome and not meeting criteria for any other major psychiatric disorder); Poor outcome (e.g., severe handicap with no major psychiatric disorder but with clear verbal or non-verbal communicative skills); and Very poor outcome (e.g., severe handicap, unable to lead independent existence, no clear verbal or non-verbal communicative skills)</td>
<td>- 26% of those with AS had a restricted or poor outcome; 27% had a good outcome and 47% had a fair outcome  - Lower FSIQ contributed to poorer outcomes for those in the AS group.  - The AS group revealed a stable overall IQ over time in contrast with a decline of intellectual ability in the Autism group at follow-up.  - 17% of individuals in the AS group had GAF scores above 70 (indicating normal/near normal psychosocial functioning)  - 84% of the AS group maintained a clinical diagnosis at follow-up.</td>
<td>Weaknesses: 1) The contrast between the two groups may not be ideal because of the much lower IQ for the Autism group; thus, the study was only able to match on age. 2) Despite the authors belief that the two groups were considered &quot;roughly comparable&quot;, it would be more advantageous to match the AS group with a neurotypical sample in order to control for the effects of IQ. 3) No females formed part of the study.</td>
</tr>
<tr>
<td>Jennes-Coussens et al. (2006)</td>
<td>Compare quality of life (QOL) of individuals with AS during early stages of transition to adulthood matched to controls. 12 males (Mage 20.3 years) with AS matched to 13 controls(Mage 20.5) on age and verbal IQ.</td>
<td>1) Two self-administered questionnaires were completed: (brief version) and the Perceived Social Support Network Inventory.  2) A semi-structured interview was conducted that probed for information pertaining to independence, leisure activities and social relationships.  3) Wechsler Intelligence Scale for Children – Third Edition(Wechsler, 1991)</td>
<td>- Those with AS reported a significantly lower social and physical QOL when compared to the control group.  - Education, living arrangements and number of friends were similar between groups.  - Those with AS reported less positive employment experiences and preferred solitary activities.</td>
<td>Weaknesses: 1) Small sample size. 2) At the time of the study, there was no confirmation individuals in the AS group continued to meet the criteria for the condition despite having received a diagnosis years earlier.</td>
</tr>
</tbody>
</table>
(Renty & Roeyers, 2006). Investigating the predictive value of disability and support characteristics for QOL in adults with HFA.

58 adults (M age = 28.34 years; M IQ = 103.09 74.1% male) with HFA.

1) Quality of life was measured using the Quality of Life Questionnaire (QOLQ; Schalock & Keith, 1993)
2) Autism-Spectrum Quotient (AQ; Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001).
3) Interpersonal Support Evaluation List (ISEL; Cohen et al., 1985) - perceived informal support.
4) Camberwell Assessment of Needs (CAN; Phelan et al., 1995) - received informal and formal support.
5) WAIS-III (Wechsler, 2000).

- After controlling for age and gender, disability characteristics (i.e., FSIQ and AQ) did not explain significant variance in QOL scores.
- After controlling for gender and disability characteristics, support characteristics significantly contributed 51.4% of the variance in QOL scores.
- Perceived informal support (ISEL) and not received informal support was significantly positively associated with QOL (r = .55, p < .001).
- Unmet formal support needs (CAN) was significantly negatively associated with QOL (r = -.63, p < .001)

(Howlin et al., 2004) Adult outcomes for children diagnosed with autism

68 individuals (males = 61; M age = 29 years; M FSIQ = 75) meeting criteria for autism and an IQ >50. Mean age during childhood = 7.

1) Autism Diagnostic Interview (ADI; Le Couteur et al., 1989)
2) Battery of cognitive and linguistic abilities: Full Scale, Performance & Verbal IQ - WAIS-R (Wechsler, 1981); The British Picture Vocabulary Scale (L. Dunn, Dunn, Whetton, & Pintilie, 1982); Neale Test of Reading Ability (Neale, 1977); Schonell Spelling Test (Schonell & Schonell, 1960)
3) Outcome ratings: Very Good = achieving a high level of independence, having some friends/job (total scores 0-2); Good = generally in work but requiring some degree of support in daily living; some friends/acquaintances (total scores 3-4); Fair = has some degree of independence, and although requires support and supervision does not need specialist residential provision (total scores 5-7); Poor = requiring special residential provision/high level of support; no friends outside of residence (scores 8-10); Very Poor = needing high-level hospital care/ no friends/ no autonomy (total scores 11)

- IQ scores ≥ 70 were more likely to have a positive outcome.
- High social outcome ratings were associated with higher scores on cognitive, language, reading and comprehension tests. They showed a greater use of social language while abnormal language features and ritualistic behaviours were less frequent.
- Overall outcome for individuals: Very Good = 12%; Good = 10%; Fair = 19%; Poor = 46%; Very Poor = 12%

(Engstrom et al., 2003) Psychosocial functioning of adults with AS or HFA

42 individuals (M age = 30.8 years; male = 24); 32 individuals with AS and 10 with HFA.

A subsample of 16 (10 with AS & 6 with HFA) were selected for a semi-structured interview to determine social adjustment.

1) Overall social adjustment assessed using Lotter’s (1978) outcome scale: Good outcome = normal or near normal social life and satisfactory functioning at school or work; Fair outcome = some social and educational progress despite significant or even marked abnormalities in behaviour or interpersonal relationships; Poor outcome = severe handicap, no independent social progress; Very poor outcome = unable to lead any kind of independent existence.
2) Semi-structured interviews were conducted using a modified version of the CAN (Phelan et al., 1995).
3) Public and private support was assessed using the grading scale: none, low, moderate and high.

- Overall social adjustment for the subsample: Good = 12%; Fair = 75%; and Poor = 12%
- Majority were living alone, had little partner relations and limited employment.
- Majority were living independently.
- One person in a lived-in relationship.
- One person had a regular job.
- Majority required support (emotional and practical)
- No individuals were married or had children.
- Family support compensated where public

Strength: 1) The first empirical study to investigate predictors of QOL (a multidimensional construct) as an outcome variable.
Weakness: 1) The mean AQ score was quite low in this sample (29.69). Baron-Cohen and colleagues (2001) recommend a score of 32+ for clinically significant levels of autism specific traits.

Weaknesses: 1) Only 44 individuals received a FSIQ, Mean FSIQ = 75.00; thus, the data includes individuals not diagnosed with HFA.
(Larson & Mouridsen, 1997) 30 year follow-up study describing the outcome of childhood autism (CA) and AS originally diagnosed as psychotic.

9 individuals with CA (3 males) and 9 individuals with AS (7 males). Mean age: CA = 5.9 and AS = 9.2. Mean age at follow-up: CA = 39.1 and AS = 36.5 years.

1) Each of the 18 individuals met the criteria according to the ICD-10 for either CA or AS at intake. Children were grouped into four different IQ categories: Severe mental retardation (IQ < 50); mild mental retardation (IQ 51-70); nearly normal intelligence (IQ 71-85); and normal intelligence (IQ > 85).
2) Demographic information was gathered at follow-up on vocational training and occupational status, disability pension, marital status and children, residence (e.g., independent living), criminality, psychiatric morbidity and pharmacotherapy.
3) Outcome was assessed at follow-up on criteria recommended by Lotter (1978): Good, Fair, Poor and Very Poor Outcome.

- 63% of adults in the CA group had either a poor or very poor outcomes
- 13% of the AS group had a Poor outcome; 50% had a Fair outcome. No individuals in the AS group were classified as having a very poor outcome.
- In both groups, normal intelligence (i.e., IQ > 85) predicted a Good outcome.
- The majority of individuals in the AS group were registered with the labour market whereas the majority of those in the CA group had never worked.

Weaknesses: 1) Individuals do not comprise a representative sample of those diagnosed with CA or AS; 2) It was not clear at follow-up whether IQ scores remained stable for both groups; 3) The groups were not matched on gender.

Strengths: 1) Very few studies have reported follow-up studies spanning 30 years or more for individuals with AS.

(Venter et al., 1992) Follow-up study of individuals with HFA and predictive value of autism severity and cognitive skills on outcomes.

58 children (IQ > 60 [early M IQ = 80.24; current mean IQ = 79.21]; 35 males, 23 females) with HFA followed over a mean period of eight years (mean age at follow-up = 14 years). At follow up, all individuals met the criteria on the ADI.

1) Battery of psychometric tests administered over both time periods: WAIS-R or the WISC-R (Wechsler, 1981); Raven’s Progressive Matrices (Raven, 1960); Peabody Picture Vocabulary Test(L. M. Dunn & Dunn, 1981); The Schonell Graded Spelling Test (Schonell & Schonell, 1960), Neale Analysis of Reading and Enright Diagnostic Math Test (Enright, 1983; Neale, 1958); Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989)
2) Parents were interviewed using the Autistic Diagnostic Interview (ADI; Le Couteur et al., 1989) according to ICD-10 diagnostic criteria: language deviance, social deviance and repetitive behaviours.
3) The VABS (Sparrow et al., 1984)

- Verbal skills (PPVT) were the strongest predictor of outcome measures (i.e., social adaptive functioning and achievement scores).
- Current verbal IQ was the most consistent predictor of outcome measures.
- Positive associations were evident between intellectual functioning and academic achievement.
- Early patterns of restricted behaviour and language deviance predicted negative outcomes.
- Reading comprehension was the most severely delayed academic area.
- Current social deviance, verbal IQ and verbal skills predicted academic achievement.

Strengths: 1) The first known study to look at autism severity symptoms as predictors of adaptive outcome in adulthood; 2) Highlights the importance of education opportunities for autistic children and the influence this has on adult adaptive functioning.
Appendix B: Proposed Structure of Studies

Figure 1. Structure of study one: comparing psychosocial and neuropsychological functioning, self-perceptions, emotion regulation and coping strategies in adults with HFASD to matched controls.

Figure 2: Structure of study two: Examining the associations between HFASD symptomatology, neuropsychological functioning, self-perceptions, emotion regulation, coping strategies and psychosocial outcomes.
Appendix B: Proposed Structure of Studies (Continued)

Figure 3: Structure of study three: Proposed model of factors influencing psychosocial functioning for adults with HFASD.
Appendix C: Proposed Hypotheses for all Three Studies

Study One
The following hypotheses are proposed for Study One:

1.1 Individuals with HFASD will perform significantly poorer on measures of executive functioning (e.g., response initiation, suppression and conceptual switching) and social cognition as compared to matched controls.

1.2 Individuals with HFASD will report significantly poorer global social functioning than matched controls.

1.3 Individuals with HFASD will report significantly poorer mental health when compared to matched controls as indicated by: a) less adaptive coping strategies; b) higher levels of emotion regulation difficulties; c) lower self-concept; and d) higher levels of depression, anxiety and stress.

Study Two
The following hypotheses are proposed for Study Two:

1.1 HFASD symptom severity would be significantly negatively associated with measures of executive functioning (e.g., response initiation, suppression and conceptual switching) and social cognition.

1.1.1 Severity of Social and Communication symptoms of HFASD would be significantly negatively associated with measures of social cognition.

1.1.2 Severity of Rigid/Repetitive symptoms of HFASD would be significantly negatively associated with measures of executive functions that target response suppression and switching/flexibility.

1.2 HFASD symptom severity would be significantly negatively associated with social functioning.

1.3 HFASD symptom severity would be significantly related to mental health outcomes as indicated by significant negative associations with self-esteem and significant positive associations with depression, anxiety and stress.

1.4 Performance on measures of social cognition (i.e., ability to recognise sarcasm and lies) would be significantly positively associated with global social functioning.

Appendix C: Proposed Hypotheses for all Three Studies (Continued)

1.5 HFASD symptom severity would be significantly negatively associated with measures of psychological resources (e.g., self-perceptions [health-related cognitions, self-concept, perceived social support], emotion regulation and coping strategies).

1.6 Measures of psychological resources (e.g., self-perceptions [health-related cognitions, self-concept, perceived social support], emotion regulation and coping strategies) would be significantly positively associated with social functioning and mental health measures.

Where specific predictions for Study One and Two have not been made, it is of interest to explore the associations between the remaining HFASD subgroups, neuropsychological functions, psychosocial outcomes and the relevant psychological resource variables.

Study Three
As mentioned previously, SEM will be applied to test the proposed stress-buffering model of psychosocial functioning for adults with HFASD. This model will investigate the mediating and/or moderating role of psychological resources, as defined by self-perceptions, emotion regulation and coping strategies, in the relationship between HFASD symptom severity and psychosocial outcomes. As such, within this model it is expected that the following relationships would be observed:

1.1 HFASD symptom severity would be significantly negatively associated with measures of psychosocial functioning (i.e., social functioning and mental health measures).

The relationship between HFASD symptom severity and psychosocial outcomes would be moderated and/or mediated by psychological resources as indicated by self-reported measures of self-perception (i.e., health-related...
## Appendix D: List of measures, administration methods and approximate duration of testing

<table>
<thead>
<tr>
<th>Construct and Measure</th>
<th>Administration Method</th>
<th>Study</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Severity HFASD Symptoms</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>RAADS-R*</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>25 mins</td>
</tr>
<tr>
<td><strong>Intelligence</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>WASI*</td>
<td>Objective Face-to-face</td>
<td>1</td>
<td>20 mins</td>
</tr>
<tr>
<td><strong>Neuropsychological Functioning</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hayling Test</td>
<td>Objective Face-to-face</td>
<td>1,2</td>
<td>10 mins</td>
</tr>
<tr>
<td>D-KEFS Sorting Test*</td>
<td>Objective Face-to-face</td>
<td>1,2</td>
<td>20 mins</td>
</tr>
<tr>
<td>LNS*</td>
<td>Objective Face-to-face</td>
<td>1,2</td>
<td>5 mins</td>
</tr>
<tr>
<td>TASIT-R*</td>
<td>Objective Face-to-face</td>
<td>1,2</td>
<td>25 mins</td>
</tr>
<tr>
<td><strong>Psychosocial Functioning</strong></td>
<td></td>
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<tr>
<td>Social Functioning</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>10 mins</td>
</tr>
<tr>
<td>DASS-21†</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>3 mins</td>
</tr>
<tr>
<td>RSES*</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>2 mins</td>
</tr>
<tr>
<td><strong>Psychological Resources</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion Regulation</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>5 mins</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>15 mins</td>
</tr>
<tr>
<td><strong>Self-Perceptions</strong></td>
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</tr>
<tr>
<td>ICQ (Health-Related Cognitions)†</td>
<td>Self-report Online/Paper</td>
<td>2,3</td>
<td>5 mins</td>
</tr>
<tr>
<td>SFSCS (Self-Concept)‡</td>
<td>Self-report Online/Paper</td>
<td>1,2,3</td>
<td>10 mins</td>
</tr>
<tr>
<td>ISEL-SF (Perceived Support)†</td>
<td>Self-report Online/Paper</td>
<td>2,3</td>
<td>5 mins</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td>160 mins</td>
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</table>

*Note: a = RAADS-R: Ritvo Autism Asperger’s Diagnostic Scale – Revised; b = WASI: Wechsler Abbreviated Scale of Intelligence; c =  D-KEFS: Delis-Kaplan Executive Function System Sorting Test; d = LNS: Letter Number Sequencing; e = TASIT: The Awareness of Social-Inference Test – Revised; f = DAAS-21: Depression Anxiety and Stress Scales-21; g = RSES: Rosenburg Self-Esteem Scale; h = ERQ: Emotion Regulation Questionnaire; i = CCS: Cybernetic Coping Scale; j = ICQ: Illness Cognition Questionnaire; The ICQ will be modified to focus on cognitions relevant to people with HFASD (e.g., helplessness, acceptance and perceived benefits); k = SFSCS: Six-Factor Self-Concept Scale for Adults; l = l*
Does your psychologist have accredited qualifications in clinical psychology?

Clinical psychologists are specialists in the assessment and evidence-based treatment of a wide range of mental health problems, including:

- Addictions
- Attention Deficit and Hyperactivity Disorders
- Autistic Spectrum Disorders
- Bipolar Disorder
- Depression & Mood Difficulties
- Drug & Alcohol Abuse
- Eating Disorders
- Emotional & Behavioural Problems in Children
- Fears, Phobias, Anxiety & Panic Attacks
- Grief, Loss & Bereavement
- Obsessions & Compulsive Behaviour
- Pain and Somatic Symptoms
- Personality Disorders
- Post-traumatic Stress Disorder
- Psychotic Illnesses
- Recovery from Childhood Trauma
- Schizophrenia
- Separation Anxiety
- Social Anxiety
- Sleep Disorders

Ask the psychologist providing your mental health treatment what accredited post-graduate qualifications they have in clinical psychology.

To find a clinical psychologist who is a member of the Australian Clinical Psychology Association go to:

www.acpa.org.au and search:

The Australian Clinical Psychology Association (ACPA) represents only clinical psychologists who have obtained the accredited qualifications set down by the Psychology Board of Australia for recognition as a clinical psychologist.

These are:

An accredited Masters (two year) or Doctoral (three year) degree in clinical psychology;

and

A post-degree period of supervision to bring the total of post-graduate training to four years.

In choosing an ACPA Member you are ensuring that your clinical psychologist has completed this established standard of training.

Accredited Masters and Doctoral-level training in clinical psychology:

Provides the highest levels of training currently offered within the psychology profession in Australia

Facilitates the development of high-level, specialised skills in mental health assessment, diagnosis, and evidence-based treatment planning and implementation

Not all psychologists who are permitted to use the term clinical psychologist in Australia have completed this level of training. Indeed, some have not completed any post-graduate qualifications in clinical psychology.

International standards require post-graduate qualifications in clinical psychology for all clinical psychologists.
Engaging with the Autism Community: Beyond Tokenism?

Janine Robinson1 DClinPsy., Marie Claire Shankland2 MSc.


NHS Education for Scotland is a special health board, responsible for supporting NHS services by developing and delivering education and training for those who work in NHS Scotland.

Abstract

The increased interest in autism is evident, but whether there is true agreement in the directions for autism research and service planning amongst researchers, practitioners and the autism community is less so. The autism community report that they are excluded from the process of such research and planning. If enabled to engage in a collaborative process, that is strategic, well-planned and embedded in policy, the community can contribute in a meaningful way to the direction of research and planning of services. The Scottish Strategy for Autism (2011) provides an example of strategic planning, and investment in collaborative partnerships by meaningful engagement with the autism community. The NHS Education for Scotland (NES) Autism Training Framework (2014) benefited from this national and strategic foundation. The autism community was actively involved in developing a framework of autism knowledge and skills for staff working in health and social care across Scotland.

Background

Individuals affected by autism spectrum conditions, their families and carers—henceforth referred to as ‘the autism community’ in this article—appear to have increasing opportunity to express their views regarding their service needs (Barnard, Harvey, Potter, & Prior, 2001; Rosenblatt, 2008; Steward, 2008; Withers, 2008; Daly, 2008; Catterson, et al., 2013) and directions for research (Wallace, Parr, & Hardy, 2013). Nonetheless, a recent detailed report in the UK found a significant discrepancy between what the autism community regarded as research priorities and the actual research being conducted, primarily in understanding the “underlying biology, brain and cognition of autistic people” (Pelicano, Dinsmore, & Charman, 2013, p.5). The report argued for greater investment in research areas “that affect the day-to-day lives of autistic people and their families – research on public services, life skills, cognition and learning and the place of autistic individuals in society” (Pelicano, et al., 2013, p.5). The authors further recommend more collaboration between research funders, researchers and the autism community “in order to advance progress in UK autism research and make a real impact on the lives of autistic people and their families” (Pelicano, et al., 2013, p.5). Such collaboration would understandably require effort and time, but formal partnerships would facilitate the active involvement of the autism community at various levels of the research process, including the ultimate outcome of translating research findings to the day-to-day concerns of the autism community.

Of interest to those working in the health and social care sectors, when the autism community and practitioners in the UK were asked to rate priorities for autism research, there was general consensus of a need to focus on life skills for people with autism, to understand how people with autism think and learn, and identifying how public services can meet the needs of the autism community (Pelicano, et al., 2013). This does not exclude the need to continue with research into biological, neuropsychological and genetic factors; merely addressing the current significant imbalance.

In spite of general consensus, the experience of engagement in research does not appear to be shared by the researchers and the researched. The autism community commented on key elements of the experience, such as the fundamental attitude of the researcher and the lack of feedback about the outcome of the study. Barriers to engagement were not fully understood or taken into account. For example, educational material that is not available in language that is suitable for a lay person, the complexity of people’s lives and lack of available time, given their involvement in the life of the person on the autism spectrum; and identifying research that may be of value or interest to their lives (Pelicano, et al., 2013). Given this detailed, if not sobering report concerning the mismatch of priorities (and experience) of researchers and funding bodies compared with the expressed views and hopes of the autism community, we may wish to consider how well health and social care agencies fare in this regard.

The Scottish Context

The Scottish Strategy for Autism was launched in 2011, with clear directions, a ten-year timeframe and 26 recommendations to be met in 3 stages (The Scottish Government, 2011). The Autism Strategy Reference Group (The Scottish Strategy for Autism, 2013) was established along with six further subgroups, each allocated key areas of responsibility, viz., cross-agency collaboration and involvement, wider opportunities and access to work, research and achieving...
best value for services. Subgroup 3 addressed matters of diagnosis, intervention and support and one key outcome of this work (The Scottish Strategy for Autism, 2013a) was to develop guidance on interventions for those on the autism spectrum (The Scottish Government, 2013a). Subgroup 6 consisted of the autism community and representatives from the Scottish Government, along with key professionals (The Scottish Government, 2013b). Stakeholders from across the country have participated in the process of planning and implementing the key recommendations: the Scottish Government; Scottish Health Boards and Scottish Local Authorities; voluntary sector organisations and independent organisations providing autism services, along with education and training establishments and representatives of the autism community across Scotland. The Psychology Directorate at NHS Education for Scotland (NES) was invited to develop a training framework that would outline what all staff in NHS and social care services would require in terms of knowledge and skills in autism, in order to meet the needs of individuals with autism, their families and carers.

**Key collaborative tasks**

In keeping with the approach of the Scottish Government regarding involvement of the autism community in the Scottish Strategy for Autism, NES identified key areas for comment and involvement from the autism community. Initially, this involved a small group of representatives carrying out a focused review of an existing NES autism web resource for primary care practitioners (NHS Education for Scotland, 2006). The NES team presented the autism community with an update of progress at a Subgroup 6 meeting, with requests for examples to be shared of experiences of good autism practice. Practitioners also conducted a review of the material and feedback from both groups contributed to the updating of the web resource (NHS Education for Scotland, 2006) and the development of an e-learning module for primary care practitioners. Key themes gathered from the reviews further informed the content of the training framework during its development.

The NES Autism Training Framework (NHS Education for Scotland, 2014) was developed and refined over a period of ~one year, culminating in a substantial document (and web-document) which could be used by individual practitioners, their managers or service leads, to identify the autism training needs of staff employed in various roles in health and social care settings. Given the valuable input of the autism community in the earlier focused task of reviewing the web-resource, it was evident that the voices of the autism community would provide unique material for the document. A consultation event was hosted in collaboration with Autism Network Scotland (an organisation established as a hub of impartial direction to services for those affected by autism and a platform for professional networking, good practice and research discussions). Invitations were sent to a broad range of individuals affected by autism, including families, carers of those diagnosed with Asperger’s syndrome and those with significant mental and physical health needs. The session aimed to introduce the framework prior to a workshop used to generate ‘real life’ examples of how the knowledge and skills described in the framework would help improve the experience of services for people with ASD, their families and carers. Verbatim comments were recorded and selected to populate the main document. The NES Autism Training Framework (NHS Education for Scotland, 2014) is hence the result of contributions from practitioners, organisations and the autism community, on the firm foundations of a national autism strategy.

**Key outcomes**

The NES project was not without its challenges. Attempting to engage with a range of stakeholders in a timely manner during a short-term project presents difficulties. Feedback from some areas of the community indicated that our initial expectations were too high – given the pressure of time and invitations for responses were unrealistic. More preparation and time was allocated for the second phase, viz., the consultation and group discussion, and greater attention was paid to the practicalities of people being able to contribute. For example, participants were refunded expenses for attending and lunch was provided, the meeting was held early afternoon to facilitate attendance, and participants were invited to send further comments from the day via email or post.

**Discussion - Common barriers**

Common purpose: An autism training framework needs to consider the views and needs of those it is purporting to serve. Nonetheless, that framework is designed be used by practitioners, managers and service leads as well as training providers in considering how best to deliver training of the workforce that makes a difference to the quality of life and the experience of the autism community when accessing services. The framework may not be fully accessible to the autism community, nor would they be able to comment on all aspects of it, but they would nonetheless be able to make a valuable contribution to the work.

Terminology: Questions of terminology commonly create tensions, such as *impairment* versus *difference*, *disorder* versus *condition*, and *person with autism* versus *autistic person*. Documentation being used nationally across the workforce needs to be consistent in its language. It also needs to be consistent with much of the scientific and clinical literature internationally. Opting to retain ASD over ASC is one such example. Whilst recognition of individual preference for terminology is essential, the framework exists in the context of a national autism strategy, national and international guidelines and maintaining consistency of terminology seeks to reduce confusion. However, educating the workforce in the need to respect the views of the autism community and how they may wish to identify themselves or their relatives is fundamental to the process of ensuring that individuals do feel heard, respected and part of the process.

Stereotypes: Engaging in a real way with individuals on the spectrum, their families and carers requires careful consideration if it aims to be meaningful and of benefit to all
involved. Addressing stereotypes is fundamental to proper engagement.

Facilitating engagement: To move beyond the sense of self-congratulation that we are involving the autism community, we need to reflect on the facts: many individuals and/or carers may not be in paid work; may not have the time or resources to devote to attending meetings that professionals, on the other hand are paid to attend. We need to move beyond feeling that we are doing this for them.

Investment: The NES project was made possible by the networks already established by the Scottish Government ASD Reference Group and demonstrates that time invested in developing those links can then bear fruit for other projects, including research.

Investing time and resources into the process of inclusion is imperative to establishing relationships and collaborative practices that are sustainable. Following the lead of some research funding bodies, which support projects that demonstrate collaboration and involvement of the autism community, we can ensure from the outset, that engagement factored into service planning and consequent costs with respect to time and resources.

Strategic planning: Locating change within broader local and national strategies provides a structure and process in which collaborative partnerships can be embedded. This can support the development and coordination of good practice guidelines and standards for engagement with people with autism, their families and carers.

Conclusion

With financial constraints contributing to pressure on clinical and social services as well as funding for research, informed decisions need to be made in order to invest in appropriate education, training and support so as to make a real difference to the lives of those on the autism spectrum, their families and carers. Information gathered systematically from the autism community, not only researchers and practitioners, will provide the optimal information on which to make informed decisions. In the context of national and international guidelines (National Institute for Health and Care Excellence, 2014; Scottish Intercollegiate Guidelines Network, 2007), national strategies, (The Scottish Government, 2008; The Scottish Government, 2011) and implementation plans (The Scottish Government, 2008), opportunities are available for active engagement with all stakeholders.

Lessons learned from the Scottish experience suggest that timely, focused engagement with clear directions and expectations from the start and a basic mutual understanding that any engagement is for mutual benefit is possible. There is no guarantee that agreement will be reached, or that true representation is possible, but if the process is established with the right attitude and approach and is embedded in policy, successful engagement is more likely and the impetus for change established.


References


Can you tell us a little bit about what you’re doing, where you’re working and some of your interests?

I currently work for Autism Spectrum Australia (Aspect) in their Communications team. I also have a long love for all kinds of stories, whether it is television shows, movies and comic books.

What have been harder for you than it might be for others?

Growing up, I had difficulty with time management and understanding other people’s reactions or behaviours, such as sarcasm. As time has gone on, I have gotten better. Sure, there have been some slip ups as time goes by, but today they are rare.

What have you done to overcome challenging obstacles?

I have my fair share of ways to overcome obstacles. Currently I am learning a lot of independent activities. I just built my first computer, I am cooking more and I want more independent projects. Long ago I thought that if you keep hacking at something you will eventually get it. Sadly this is only true some of the time.

As time has gone on, I’ve realised there are alternative ways to solving a problem. My latest method is to research as much as you can on a topic before you tackle a project, a problem or whatever you do. I also believe that it is good to have a lot of people to look on a project and have them offer their advice.

What’s something that people may not know about those on the spectrum?

The big thing that people don’t understand about autism is that we’re all different. When you have met one person on the spectrum, you have met one person on the spectrum. When it comes to people with autism, don’t treat them like the last person with autism, or compare them to fictional celebrities like Sheldon Cooper.

How do you feel about common stereotype of people with autism being compared to characters like Rain Man or Sheldon Cooper?

I hate how people constantly say to us, “Oh you’re like Sheldon Cooper or Rain Man”. It gets really annoying, because there are many things that they can’t do that plenty of us can do. This means we have to deal with a ludicrous stereotype that is set up by someone who doesn’t truly understand us.

What’s something that people may not know about you?

That’s a hard one. People don’t know that I’m a walker. I love all kinds of walks, mainly because I usually have my head in front of a computer screen for most of the day. So I need a little bit of time to help my brain relax and have a little bit of exercise. Usually I will take my note pad with me so I can collect my thoughts.

You may have had meetings with professionals who work with people on the spectrum in the past (such as speech pathologists, occupational therapists, employment services). If there’s one piece of advice you would give professionals on how to better service those with autism, what would it be?

I would say that books and theoretical stuff can only take you so far. If you want to be really great, you must be fearless and understand the world that the person in the spectrum is in. You must understand what makes those on the spectrum tick and why they may be sensitive to certain sensory things - whether it is sights, sounds, smells, touches or even tastes. All of these sensitivities are necessary to understanding someone on the autism spectrum.

What do you think makes you different, quirky or unique to others?

I am eccentric and I’m a bit full on when I meet new people. This means when it comes to romantic relationships, women can get deterred by my forwardness. I have found methods around this though. By remembering my past mistakes, I restrict my emotions so that they don’t come at people like a hurricane.

If you could tell the world one piece of advice to better understand those on the spectrum, what would it be?

I would say to be mindful of the emotions that one is going through whether they are on the autism spectrum, deaf or don’t even have a disability. I have heard so many stories about how a child with autism is having a meltdown and people judge the mum or dad for being a bad parent. That’s just wrong.

I was recently at a round table discussion on disability, and the judicial justice system. We talked about how more judges need to understand that the people with the disability are affected by the environment around them. So before you judge someone on how they are behaving, ask them what their current environment is doing to them and I’m sure you’ll get a better insight into how they’re feeling.

John’s Perspective

When did you first notice something about Thomas which triggered the thought that he may be on the spectrum?

Thomas’ mum, Jody, noticed earlier than me that there was something there. We really didn’t know anything about autism. I had never heard of Asperger’s syndrome until Thomas’s counsellor, Mary, called us in and asked if we could have him examined by a psychologist.
Jody would worry about Thomas’ high temperatures as a baby, late speech development, obsessions with collecting and how everything had to be placed in a certain way. She would raise these concerns to me but I would brush it aside saying it would work out in the long run or as he grew up. What I couldn’t understand was Thomas’ lack of coordination and timing in playing soccer. While kids around him were progressing, Thomas was trying really hard but not going anywhere.

We thought that autism was something that really stood out in someone and therefore didn’t initially consider it. It wasn’t until we had to move that his life was turned upside down. The bullying and lack of caring by a majority of teaching staff at his school exceeded all acceptable tolerances. We could have sent him to another school but we knew it wouldn’t help him.

Jody suggested, and I finally agreed, that Thomas should see a counsellor because he was seriously depressed. Once Mary interviewed Jody, and then at another date me, it was like a scary revelation when she explained autism and Asperger’s to us. Yet at this point in his life (16 years old), I was frightened at how Thomas was going to successfully complete his education as he was still getting bullied and was close to sitting his year 10 certificate and then Higher School Certificate. I still wonder how he achieved the fantastic results he did considering the bullying – he is nothing short of amazing. It just goes to show if someone gives you a fair go at something you are passionate about and are good at, then they would have an ace up their sleeve.

What’s one thing you would tell a parent who has recently received a diagnosis of autism or what’s something you wish you would have been told?

I suppose the main thing when parents find out their child has autism is not to panic. A diagnosis is a revelation, a light to a path, a path to how to understand what your child has and the best ways to deal with it all.

Give your child love and understanding. I feel the best way to do this is through positive reinforcement. When they make mistakes or fall short of the mark, express the good that was achieved and the choices that could have been made to achieve a better result.

As a parent you tend to kick yourself that you did not do something sooner or you question your own integrity. Every parent loves their children equally and unreservedly. By beating yourself up about not acting earlier you are holding back on the love your children are in need of.

You may have had meetings with professionals who work with people on the spectrum in the past (such as speech pathologists, occupational therapists, employment services). If there’s one piece of advice you would give to professionals on how to better service people with autism and their families, what would it be?

Our advice to professionals is to be more empathetic with these people who have been diagnosed. Understand that even high functioning people on the autism spectrum are still very quickly labelled and pigeon-holed. These people are way behind the eight-ball. Let me just relate a story here to you.

After Thomas was found to have Asperger’s, he had left school and was looking for a job. I had to take him to Centrelink in Penrith. This was for the purpose of government employees there finding out Thomas’s skills and capabilities (which is a lot). The unhelpful man who interviewed us there was quick to tell us that he was the qualified one in the room and he would be making the judgement. He told me I was not to say a word and that Thomas was to answer all questions. By the second question, I either coughed or winced and was told to leave. We had the psychologist report with us and presented it to him. After fifteen minutes Thomas emerged from the interview room. Within the week this clown had made the call that there was nothing wrong with Thomas and no assistance would be given. Mind you having said this we have met some fantastic people at Centrelink who have been a great help to Thomas.

As a parent, is there something you wish that society could do or say to better understand those on the autism spectrum? If so, what would that be?

To society we would like to say it takes all kinds to make this world great. People on the spectrum are one of the cogs in the mechanism that makes this world go round and interesting. To patronise and then categorise makes you worse than the person you think you are.

Find time to listen, look and understand people who are different. You might just learn something about yourself to make you a better person. When I was young I used to marvel at how the old people would sit on the veranda and talk about how society was a lot closer in the past. Back then people would help each other, stop and talk a while, look after each other and their properties. Now I am the grey man making those same statements.

Is society becoming a media categorised community? Are the two main social requirements today self-obsession and materialism? Is loneliness and injustice so acceptable that rather than find solutions, excuses are easier? If I could turn back time!

Do you have any memories of Thomas from when he was a child that sums up his creative and unique way of thinking or acting?

The memories of Thomas as a child that sum up his unique way of acting and thinking! He was never embarrassed with doing or saying something if he enjoyed it or saw others getting a kick out of it.

He once auditioned for the main role in the school play ‘The Wild Things’. Placing a bin in front of the class, the teacher asked students to come up and show what they would do with the bin if they were the wild thing. When Thomas’ turn came he destroyed the bin, got the part and drama was never the same in school again.

Thomas has always put everything into whatever he has had to say or do. He has never wanted to hurt anybody even at the worst of the bullying. He hates seeing people hurt.
We’re sure Thomas inspires you all the time, if not every day. As part of Aspect’s latest positive awareness campaign, ‘a different brilliant’ which celebrates the differences of those on the spectrum, can you tell us something we may not know about him that you celebrate?

If there is one thing that stands out to celebrate about Thomas it is this - we thank God every day for giving us the privilege, the joy and excitement of raising such a wonderful person. His laughter, talk and emotions are something we live for every day, and he provides them by the bucket load.
Early Career Clinical Psychologist Forum Report
Matthew Csabonyi, MPsych. (Clin.)
ACPA – Victorian Committee

On the 21st of March 2015, seventeen early-career clinically-trained psychologists convened for the first early career clinical psychologist forum in Australia. ‘Early-career’ was defined as including those within five years of completing the requirements of a masters or doctorate program in clinical psychology. The forum was held at The University of Melbourne and was funded and supported by the Australian Clinical Psychology Association (Victorian Committee).

The purpose of the forum was to convene a group of early career clinically-trained psychologists (ECCPs) to discuss a set of key questions regarding the issues early career clinical professionals are currently facing within their profession. The key questions were designed to identify both the issues and potential solutions so that clear recommendations could be made for relevant stakeholder organisations to address them. The main organisations considered relevant for addressing early career issues were the Australian Clinical Psychology Association (ACPA), the Australian Psychological Society Clinical College (APS CCLIN), and the Psychology Board of Australia (PBA).

Four key stakeholder representatives presented to the ECCPs on the early career psychology perspective, the national committee of ACPA, the clinical registrar supervisor’s perspective, and the public employer’s perspective. The presentations addressed three key questions: ‘What are the main issues affecting early career psychologists from your perspective, both in the workplace, in your organisation, and in the profession more generally?’; ‘What do you see as potential solutions or ways forward to address these issues?’; and, ‘What is your role or your organisations role in addressing these issues and how is that currently occurring?’.

Following the stakeholder presentations, the ECCP participants took part in discussions in whole-group and small-group formats, reflecting on key points from the stakeholder presentations, and then addressing three key questions: ‘What are the three most important/concerning issues affecting early career psychologists?’; ‘What are potential solutions or ways forward to address these three issues?’; and ‘What would we like to see our professional societies or associations doing to address these three issues?’. The answers to these questions were collated in a whole-group discussion, and an individual exercise completed where participants chose their preferred issues and solutions to address from the collated material. The most popular issues and solutions discussed by the participants are presented below.

ECCP Issues

1. Undervaluing of ECCPs

Lack of knowledge regarding the depth and breadth of clinical psychology training and lack of understanding of the registrar program were identified as contributing factors to ECCPs being undervalued within both the public and private sectors. Many participants reported having been treated by employers as trainees within their roles despite being fully registered psychologists having completed the same level of training as most clinical psychologists.

ECCP requirements for supervision and professional development were identified as another contributing factor relevant primarily to the public sector. Participants raised concern that the cost of providing for these requirements is a deterrent for employers in hiring ECCPs, making ECCPs undesirable in comparison to potential employees from other disciplines with fewer ongoing costs.

2. Impact of the registrar program on finances

The cost of supervision was reported as the major impact (approximately $6,500 per year and quadruple the requirement of other registered clinical psychologists), as well as the cost burden of completing 40 hours of professional development (double the requirement of other registered clinical psychologists). Many workplaces do not fund the required supervision or appropriate professional development (even in the public sector, some workplaces only fund professional development that registrars consider to be below their competence level, such as introductory workshops or basic training courses).

3. Impact of the registrar program on self-care

Isolation, burn-out, and lack of support were reported as common experiences. Participants were concerned that because registrars wish to finish their programs as quickly as possible, many will stay in undesirable or unsafe workplace situations in order to accomplish this. Situations where registrars experience significant levels of bullying, are encouraged to behave unethically, witness frequent unethical behaviour, are delegated a majority of highly complex clients, or experience difficult or inadequate supervisory relationships, were provided as common examples.
Participants also reported that the list of competency areas outlined by the PBA for clinical psychology registrars is unrealistic and unattainable for most registrars in their workplaces. Participants reported that given the current difficult job market for ECCPs, they are often unable to strategically choose employment the way that many clinical psychologists were able to in the past. As a result, participants reported needing to spend unreasonable amounts of time outside of their full-time work attempting to gain competence in all of the competency areas required by the PBA for their programs.

4. Lack of evidence of competency outcomes

Importantly, participants acknowledged and supported the need to continue to raise standards for clinical psychology training in Australia. However, they expressed concern about the validity of the registrar program in accomplishing this, and the lack of evidence demonstrating its effectiveness. Participants were concerned that continuing to raise standards without evidence of real outcomes would merely ‘pay lip-service’ to raised standards and lead to further burn-out of ECCPs with no competence benefit. Participants considered that if there was no evidence that ECCPs who have completed the registrar program were more competent than ECCPs who did not complete it, then the process of the registrar program itself should be reviewed.

5. Limited job opportunities

In the public system limited job opportunity was particularly related to the increase in generalised roles over specialised roles. Participants reported that generic roles (such as “mental health clinician” or case-management roles) often do not make use of the skill-set of an ECCP. Participants reported that ECCPs are often valued less in these roles than other disciplines because psychologists are not primarily trained in case management and are significantly more expensive than other disciplines because of the amount of supervision and professional required (particularly for registrars). Participants also reported needing to down-play their skills and level of training in their workplaces in order to avoid being perceived as elitist or arrogant, to maintain relationships, and to avoid discrimination or poor treatment.

In the private system limited job opportunity was related mostly to poor salaries and high costs. For example, participants reported that many ECCPs bulk-bill clients, but pay approximately 40 percent of their income to their employers, leading to unreasonable take-home pay-rates (as low as $160-$200 per day). Likewise, in salaried positions ECCPs were reported to experience difficulty negotiating reasonable pay rates because of the work shortage for their cohort and the availability of workers from other disciplines. In comparison to other six- to eight-year trained professionals (such as lawyers or physicians), participants reported that ECCPs are under-remunerated considering the time, effort and competition involved in completing eight years of clinical psychology training.

In both the public and private system participants reported that there is a small number of ECCP positions available relative to the increasingly large number of ECCP graduates. Participants also reported unequal division of labour as a significant issue in both the public and private sectors for ECCPs. For example, participants reported often being delegated a higher number of very complex clients within teams than other workers even though work roles are the same and salary between disciplines is comparable.

6. Lack of voice

Although ECCPs represent a large portion of the clinical psychology profession, they are under-represented at all levels of the profession. They are rarely represented at meetings where decisions are being made, and consultation from ECCPs is rarely sought when changes are being considered within the profession, even though ECCPs are often the primarily impacted cohort by those decisions and changes. Additionally, there are few ECCP representatives on either state or national committees either within the APS, ACPA, or the PBA (this is currently being addressed by both APS and ACPA, although currently there are no ECCP representatives within the PBA).

**ECCP Solutions**

1. **Guidelines for private employers**

Professional societies should provide clear guidelines for private employers regarding appropriate levels of remuneration for both salaried and contracted employees. Recommendations should also address the trend in paying a percentage of earnings to the employer (i.e., is this the equivalent of paying for referrals?). Recommendations should also be provided regarding provision of supervision (or a portion of required supervision).

2. **Guidelines for clinical psychology supervisors**

Professional societies should provide clear guidelines to private employers regarding provision of supervision at reasonable fees, or should consider recommending a reduced flat-rate of supervision fee for registrars.

3. **40:20:10 approach to supervision**

The PBA should consider changing the 40 hours of supervision requirement for each year of the registrar program. A step-down approach is recommended in order to make the requirements financially attainable for registrars, as well as to represent growing competence during the program. For example, in the first year 40 hours of supervision may be required, then 20 hours in the second year, and finally 10 hours once endorsed.

4. **Representation**

Professional bodies should consider introducing quotas for early career clinical psychologist representatives on national and state boards and committees. These roles must be genuine consultative roles rather than token roles, or roles where the primary objective is recruiting new members from the ECCP cohort to an organisation. Additionally, the PBA should consider introducing quotas for seeking consultation from early career clinical psychologists for decision-making purposes.
5. Educate the public

Professional bodies should consider focusing more attention on educating the public about the clinical psychology profession. Clinical psychologists are a small cohort in the mental health arena. Education of the public and engaging them in advocating for clinical psychologists is therefore necessary in order to effect significant change in Australia. Participants felt that the public often hold negative perceptions of clinical psychologists (e.g., greedy, over-priced, easy jobs – although participants felt the opposite is true). Professional bodies should consider utilising current media tools such as Facebook, Twitter or various advertising spaces such as print or internet advertisement. Professional bodies should consider including consumer advocates in roles at all levels of our professional associations and committees. Including consumer advocates in our committees will assist the committees to understand how to best market our profession to the public and will empower the advocates with greater knowledge so that they can educate the public effectively about our profession.

6. Educate employers

Professional bodies should consider methods of educating employers of ECCPs and advocate on their behalf. Participants would like education and advocacy to focus on ECCP competence rather than the needs that ECCPs have for further training. Participants would like professional bodies to find ways of continuing to raise standards for the profession whilst at the same time advertising ECCPs current competence to their potential employers.

7. Professional body websites

Professional bodies should consider providing ECCPs with dedicated portions of their websites or email list-serves, and should consider providing ECCPs with a dedicated ECCP budget. This will assist ECCPs to connect with one another, enable networking, limit isolation and create a potential source of job applicants for employers.

8. Collect evidence

PBA to consider collecting evidence or outcome measurement data to demonstrate the outcomes of the registrar program in terms of ECCP competence. Data should also be collected regarding the psychological and financial impacts of the registrar program so that this can be considered when deciding on further changes to training.

9. Clarify the future of training

PBA to consider clearly addressing ECCP concerns about possible further changes to training requirements. Participants would like the PBA to provide clarity about the long-term vision and trajectory of clinical psychology training requirements, and for ECCPs to have direct involvement in strategic planning.

10. Promote strengths of clinical psychology

The tension between psychology disciplines in Australia was raised by participants as negatively impacting their experience of the profession. Participants reported that the negative stance of some professional bodies (both clinical and non-clinical) towards other psychologists is a deterrent to joining those bodies. Participants would like professional bodies to focus on promoting what clinical psychologists can offer employers and patients due to their training and avoid negative messages about the skills or competencies of other psychologists. Participants felt that this was especially important between the endorsement areas of psychology in which the length of training requirements are the same as clinical psychology.

On behalf of ECCPs in Australia and the participants of the forum, the author thanks the Australian Clinical Psychology Association for their support of the forum. Please note that the views expressed in the above report are not necessarily those of the author, but are representative of the outcomes of discussions by the seventeen ECCPs at the 2015 Early Career Clinical Psychologist Forum.
Expressions of Interest

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October Issue

Supervision, Mentoring and Reflective Practice
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The Australian Clinical Psychologist provides for the dissemination of knowledge on topics of interest informative to clinical psychologists. Its focus is on the latest clinical theory and research relevant to clinical practice, including assessment, treatment intervention, training, and professional issues.

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Submissions to the Australian Clinical Psychologist may include:
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An Abstract should accompany each manuscript: word limit 100–150 words.

Use Australian-English spelling. References must be according to the American Psychological Association (6th ed.) style. Ensure that both in-text citations and references in the Reference list are in the correct format, and are accurate and complete. It is preferable to use EndNote.

All text submitted must be original. The paper should not have been published, or be under submission, elsewhere.

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October Issue:
Supervision, Mentoring and Reflective Practice

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