# Aspect Comprehensive Approach for people with autism spectrum disorder

## Background theory and literature

Autism spectrum disorder (ASD) is a lifelong developmental disability characterised by marked difficulties in social interaction, impaired communication, restricted and repetitive interests and behaviours, and sensory sensitivities. ASD includes autistic disorder (or 'classic' autism); Asperger's disorder; and pervasive developmental disorder not otherwise specified (PDD-NOS), also known as atypical autism.

## The Aspect Comprehensive Approach (ACA)

Autism Spectrum Australia (Aspect) has been providing support to people with ASD and their families since 1966. It is now the country's largest not for profit autism-specific service provider working with 10,000 people and families annually across Australia. Aspect's specialised education program, operating through eight schools, around 100 satellite classes and an itinerant educational outreach team, is the largest autism-specific program in the world.

The ACA is derived from some 50 years of operating services for people with ASD. It is based on a set of principles, founded on collaboration, capacity building and evidence-informed practices applied across all settings relevant to the person with ASD, including Aspect services, the person's home and their community.

The ACA provides for collaboration between the person with ASD, their families and carers, professionals and community agents. Aspect services place the people we support at the centre of everything we do by combining individual needs and wants with ASD specialist programs that include evidence based practice and therapeutic approaches.

The ACA is built upon seven core principles, which are:

1. Inclusive of the whole of the autism spectrum.
2. Person-centred and family-focused so that the individual with ASD can achieve a personally meaningful life, independence and autonomy.
3. Use of evidence-informed autism-specific tools and approaches.
4. Acknowledgement of and focus on the particular interests, strengths and contributions of the individual with ASD as the basis for establishing meaningful outcomes.
5. Collaboration among people with ASD, their families and carers, community supports and professionals.
6. The continuous development of expertise in ASD by specialist staff.
7. Building the ASD capacity of the wider community.

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# 1. Inclusive of the whole of the autism spectrum.

Autism is referred to as a 'spectrum' disorder because the range and severity of the difficulties experienced by people with ASD can vary considerably. Every individual on the autism spectrum faces challenges to some degree with social skills, communication, and flexible behaviour, yet no two people with ASD will present with exactly the same profile or expression of these characteristics (Simpson, 2001).

At a broader level, there is wide variability amongst people with ASD with regard to:
- adaptive behaviour (skills to cope with day-to-day life)
- intellectual ability
- comorbid medical or mental health conditions.

The forthcoming revised edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) acknowledges this extreme variability in the presentation of ASD, and the associated difficulty of delineating individual syndromes within the autism spectrum. As such, DSM-5 combines the previously differentiated autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified, into a single syndrome (autism spectrum disorder).

In addition to these practical considerations behind its inclusive approach, the ACA recognises philosophically that every person on the autism spectrum has an equal right to access services and supports appropriate to their strengths and challenges. The diversity and complexity of autism as a disorder means that a 'one size fits all' approach is not effective for people with ASD. The ACA intentionally considers and caters for all people with ASD, including those classified as 'high functioning' (without an intellectual disability), whose needs may be just as acute as those with intellectual impairment and yet are often overlooked (Mordre et al., 2011).

# 2. Person-centred and family-focused so that the individual with ASD can achieve a personally meaningful life, independence and autonomy.

Within the context of disability service provision, person-centredness is both a philosophy and a model of practice. It places the person with a disability at the centre of their support and enables the person to lead and have control over important decisions that affect their lives. There is an emphasis on mobilising and strengthening the individual's natural 'circles of support' within their family and social networks, as well as facilitating their access to professional services and community-based supports.

At the heart of the person-centred service system lies the process of person-centred planning, whereby the individual is supported to identify their capabilities, needs, goals and aspirations, and to navigate and prioritise support options relevant to these. Person centred planning is positive, inclusive and concerned with the whole of an individual's life; not just their need for services. Plans are kept 'live' and undergo continual review and revision as the individual's needs and circumstances evolve.

There is an emerging body of evaluation literature supporting the person-centred approach, including longitudinal studies by Robertson et al. (2005) in the UK, Robson & Dickson (2011) in Australia, and Hagner et al. (2012) in the US. All of these authors found that, for people with a disability, having a person-centred plan was associated with positive outcomes such as increased community involvement, better connectedness with friends and family, and a greater sense of empowerment, self-direction and satisfaction. The Ageing Disability and Home Care (ADHC) Discussion Paper Living Life My Way (ADHC, 2012) concludes that person-centred approaches promote well-being, independence and fulfilment for people with a disability and their families.

One of the defining elements of the person-centred approach is its inclusion of the individual's family as partners in the planning process (Povey, 2009). Family members are valued for their capacity to contribute information and insights that will permit the creation of a truly individualised set of goals, priorities and strategies for the person with a disability. Among other things, a person's family may hold extensive knowledge of their character traits, preferences and dislikes, areas of strength and difficulty, medical, educational and employment history, prior experiences with services, and likely response to new interventions.

In addition, the person-centred framework recognises that an individual's perspectives on what constitute meaningful goals and satisfying lifestyle choices may be reflective of traditions, beliefs and values that are embedded in their family context and upbringing. An effective person-centred approach will acknowledge and respect these family 'stories' as underpinning and guiding the individual's plans and aspirations for their life (Prelock et al., 2003).

Outcomes of a successful family-focused approach to service provision will therefore include:

• the fostering of positive relationships and interactions between the person with ASD and all members of his or her family
• a strengthening of the family's capacity and confidence to assist the person with ASD to achieve a personally meaningful life, independence and autonomy
• improved family resilience and self-efficacy.

Aspect operates a person-centred and family-focused approach across all its programs and services, in line with moves by the Australian Federal and State Governments to implement a person-centred service system for people with a disability across the sector.

## 3. Use of evidence-informed autism-specific tools and approaches.

As a collective term, Evidence Based Practice (EBP) refers to approaches, techniques and tools that have yielded consistent and relevant positive outcomes when subjected to rigorous testing (Mesibov & Shea, 2011). In practice, for an intervention to be considered evidence-based, it should be validated by multiple scientific research studies published in peer-reviewed professional journals. Interventions that are primarily supported by, or publicised through, anecdotal reports, single case studies, non-refereed articles, popular magazines, the internet, and media news outlets are unlikely to meet the criteria for EBP (Boutot & Smith-Myles, 2011).

Awareness of and adherence to EBP is critically important for professionals working in the autism field. As diagnosis rates and public awareness of autism have increased, so too has the range of therapeutic approaches, techniques and tools on offer, many of which are marketed and endorsed through online social media. These interventions may come with substantial claims of success attached, despite not having been rigorously evaluated (Roberts & Prior, 2006; Stansberry-Brusnahan & Collet-Klingenberg, 2010). People with ASD and their families may be confused and overwhelmed by the plethora of 'treatments' available to them, and potentially expose themselves to interventions that are ineffective or even harmful (Marder & Fraser, 2012).

A number of authors have undertaken research and literature reviews to identify interventions for people with ASD that meet the criteria for EBP (e.g. Roberts & Prior, 2006, 2011; National Autism Center, 2009). At a broad level, there is consensus that the following factors, as elements of service delivery models, are backed by rigorous research evidence:

• individualised supports and programs
• highly structured and supportive environments
• supported transitions between settings
• functional approach to behaviour management
• family involvement.

Although research findings are an essential component of EBP, other critical factors must be taken into account when designing and delivering programs and interventions for people with ASD. These include professional judgement; data-based decision making; values and preferences of the client and their family; and the capacity of the agent to implement an intervention appropriately (National Autism Center, 2009). The ACA employs the term 'evidence-informed' in preference to the narrower 'evidence-based', in recognition of these contextual and pragmatic considerations underpinning Aspect service delivery.

Aspect contributes to the wider growth of evidence-based and evidence-informed practice through Aspect Practice Research and Innovation Unit and an ongoing commitment to its Framework for Research, Evaluation and Continuous Improvement. This framework encourages and supports research, evaluation and continuous improvement activity across all Aspect service areas, with an emphasis on integrating learning into policy and practice.

## 4. Acknowledgement of and focus on the particular interests, strengths and contributions of the individual with ASD as the basis for establishing meaningful outcomes.

This principle is a logical outworking of the person-centred and family-focused approach. In order for services and supports to be meaningful and purposeful to the individual, they must capitalise on his or her unique learning style, motivations, capabilities and aspirations. Furthermore, this will ensure that goals and strategies set down in the person-centred plan go beyond 'repairing deficits' and help the individual toward a better quality of life (Cosden et al., 2006).

It is becoming increasingly recognised that people with ASD have inherent strengths as well as difficulties (Robertson, 2010). To a greater or lesser extent, dependent on the individual, these may include:

- above average intelligence
- superior memory skills
- a large vocabulary
- analytical abilities
- visual and spatial skills
- extreme focus, precision and accuracy in task completion
- conscientiousness, honesty and reliability.

In addition, it is well known that individuals with ASD often have an intense interest in one or more specialised topics, and may devote large amounts of time to researching and discussing these. While often viewed as a barrier to successful social interactions, there are in fact many ways in which having a special interest can be of benefit to the person with ASD: for example, by providing opportunities to relax and 'de-stress', bolstering their motivation, developing their problem-solving skills, and facilitating access to communities of like-minded people (Bailey, 2011). Individuals with ASD who display abilities, skills and areas of expertise that are in marked contrast to their deficits, and/or prodigious in relation to the typical population, are known as 'savants'. Recent research has suggested that as many as one in three people on the autism spectrum has a savant skill or exceptional cognitive ability (Howlin et al., 2009), though more conservative estimates put the incidence of 'savant syndrome' in the ASD population at around one in ten (Treffert, 2009).

Incorporating strengths and interests, including savant skills, into educational, vocational, therapeutic and recreational support programs can contribute to positive outcomes such as increased learning ability, improved functional skills, enhanced confidence and self-esteem, academic success, and positive employment experiences (e.g. Clark, 2001; Winter-Messiers, 2007; Hendricks, 2010; Koegel et al., 2012).

## 5. Collaboration among people with ASD, their families and carers, community supports and professionals.

The person-centred approach recognises that individuals with ASD cannot be regarded in isolation, but rather as 'nested' within complex and dynamic networks of personal, professional and community relationships. Careful attention is needed to ensure that goals and interventions are coordinated across the people and organisations that make up the individual's 'circles of support'. Poor communication or conflicting interests may result in both confusion and ineffective outcomes for the person with ASD (Breakey, 2006).

Aspect operates within a model of collaborative working in which people with ASD, their families and carers, community support personnel, and other professionals work together cooperatively and creatively, each contributing their unique perspectives to the development of a person-centred plan and to the implementation of appropriate supports and services. Within the collaborative approach, there is a respect for and open sharing of information and expertise, leading to a sense of trust, equality, mutual responsibility and accountability (Cloninger, 2004).

Research studies have explored and endorsed the collaborative approach across many areas of service provision, including diagnosis (Prelock et al., 2003), early intervention (Rowlandson & Smith, 2009), post-school transition

and employment (Chappel & Somers, 2010), and higher education (Dillon, 2007). Some of the principles for good collaborative working identified in these reports include:

- regular meetings
- defined expectations and commitment
- agreement on procedures for obtaining and sharing information
- clear definition of individual roles and responsibilities
- planning together well in advance of points of transition for the individual.

Because autism has the potential to affect so many areas of functioning, it is fitting that professionals from a wide range of disciplines should be involved in service planning and provision at the individual level. For example, a person with ASD may at once present with aspects of intellectual and/or developmental delay, sensory-motor symptoms, cognitive dysfunction, impairments in adaptive behaviour, and difficulties with emotion regulation (Reiss, 2009). The collaborative approach will therefore draw on the expertise of (among others) education professionals, occupational therapists, speech pathologists, healthcare workers and psychologists, all of whom will need to ensure that their services are flexible and responsive to accommodate the person-centred needs of individual clients and their families. The Learning Support Teams employed within Aspect schools are a clear example of this kind of multidisciplinary collaboration in action.

## 6. The continuous development of expertise in ASD by specialist staff.

Given that autism is such a complex and varied disorder, it is essential that professionals working in the field are equipped with the specialist knowledge and skills needed to effectively support people with ASD and their families on a case-by-case basis. Continuous professional development is therefore a key feature of the ACA. Aspect staff employed in client-facing roles receive a broad range of training and support to maintain and develop their knowledge, skills and confidence in working with clients and their families, as well as with colleagues, other professionals and community partners.

One of the most important objectives of professional development for Aspect staff is for them to take responsibility for their own learning, including keeping up-to-date with current evidence-informed practice, and the application of this knowledge within their service area. To this end, each client-facing division of Aspect operates and develops its staff under a specialised framework of practice derived from the core principles of the ACA and tailored to the services provided in that division.

One of the most extensive of these frameworks is the Aspect Comprehensive Approach for Education (ACAE), which is applied across all Aspect schools, satellite classes and educational outreach activities. All new Aspect school staff receive a tailored induction program including training in the ACAE elements; this is then reinforced by ongoing training provided in the school during staff meetings and professional development days. The ACAE has an associated ACAE Self-Review Checklist, which is a quality review measure and planning tool implemented annually by each school community.

Aspect additionally trains its staff in the key relationship skills needed to work effectively with families under a person-centred framework. This will include improving awareness and understanding of culturally and linguistically diverse (CALD) communities, and encouraging staff to challenge their own inherent biases and ways of thinking about difference (Prelock et al., 2003).

More generalised training and support needs for Aspect staff may relate to national and state level policy, legislation and codes of conduct relevant to the autism field, as well as organisation-specific policies and procedures. Effective professional development begins by identifying available resources and translating these resources into planned activities linked to intended outcomes (Bellini et al., 2011). This will ensure that programs remain focused, goal-directed and realistic. Other elements of successful training and development programs may include:

- a clear link between theory and practice
- the opportunity to interact and share knowledge with colleagues, clients and families in addition to learning 'from the front'
- engagement in reflective practice (Jones et al., 2006).

## 7. Building the ASD capacity of the wider community.

The final aim of the ACA is concerned with developing awareness and understanding of autism within professional groups and service sectors external to Aspect who work with people with ASD. Further, it seeks to promote the inclusion, support and contribution of people with ASD within their neighbourhoods and community networks, through providing education to the general public and community services, fostering interagency collaboration, and working with integrated service approaches such as the 'key worker' model for adults living in group homes. Aspect systematically disseminates and shares its organisational knowledge and professional expertise through a variety of channels, including:

• Aspect Practice
• the Aspect Research Forum
• presentations at conferences both within Australia and overseas
• the biennial Research Insights magazine
• an annually updated paper summarising current themes in worldwide autism research
• articles published in peer-reviewed journals.

In addition, Aspect staff regularly provide media interviews, commentary and statements relating to research and practice in the autism field.

Aspect provides community education by providing one-to-one telephone support for parents of children with ASD, together with a program of information and social events. This service is particularly targeted at parents from diverse cultural and linguistic backgrounds. Aspect additionally operates customer service for autism-related enquiries from the general public, and in support of this service publishes regular user-friendly fact sheets on 'hot topics' in autism research and intervention.

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