



Position Paper - August 2012

Autism Spectrum Disorders (ASD) and the National Disability Insurance Scheme (NDIS)

FUNCTIONAL ASSESSMENT

INTRODUCTION

It is critical that the distinct and complex characteristics of ASD are considered within all elements of the design and development of the NDIS to ensure that families and individuals experience a service response that is sensitive to their needs.

The functional assessment tools operating under an NDIS will be the critical interface between service users and the service system. As such, the barriers to inclusion, independence and social and economic participation experienced by people with an ASD must be correctly and accurately assessed and identified.

FUNCTIONAL ASSESSMENT and ASD

The functional assessment of people with an ASD must reflect the unique nature of the disability and ensure access to services that are designed to overcome the barriers to inclusion, independence and social and economic participation experienced by people with an ASD.

The Productivity Commission Report proposes that the same eligibility criteria, assessment toolbox and arrangements for assessors operate in a nationally consistent manner. Currently, there is no single assessment tool that is equipped to measure the functional needs of the diverse population of people with disabilities.

A valid and reliable functional assessment tool may address some of the potential risks of exclusion from funding for the autism spectrum community. However, in our experience, many functionally-based assessment tools are based on, and informed by, intellectual and physical disability, rather than social communication disability. Consequently, they frequently fail to measure the impact of ASDs on daily functioning and participation.

ASD is defined according to behaviour as no specific biological markers are known. Due to the variability in severity and impairment in functioning exhibited, the disorder is conceptualised as existing along a continuum (or spectrum) of severity.

Functional Assessment must clearly identify the specific barriers a diagnosis of ASD may present for individuals to inclusion, independence and social and economic participation.



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Autism is diagnosed based on the presence of markedly abnormal or impaired development in social communication and a markedly restricted repertoire of activities and interests. Significant functional impairments are evident in the areas of executive functioning and Theory of Mind and are frequently not correctly identified via assessment processes and therefore not effectively supported. Many in the autism spectrum community frequently experience problems with assessment instruments that overestimate their abilities and underestimate their need for assistance.

The use of generic disability assessment tools may be misleading, especially with individuals with ASD who have IQ within the typical range. Despite their independence in mobility, language, communication, and self-care tasks, individuals with “high functioning” ASD often have social interaction and communication difficulties, rigid and inflexible behaviours, and executive function difficulties that substantially impede their participation in education, employment and community activities. Individuals with “high functioning” ASD often have poor adult outcomes, including lower participation rates in employment than individuals with other disabilities (Shattuck, Narendorf, Cooper, Sterzing, Wagner & Taylor, 2012).

Any assessment tools utilised in the NDIS must be sensitive to the specific and distinct barriers to inclusion, independence and social and economic participation experienced by people with ASD. Further, the assessment tools must be administered by practitioners with expertise in ASD.

We call for functional assessment tools that are sensitive to the needs of people with ASD.

This will be achieved by:

- Developing and utilising assessment tools that are sensitive to the unique characteristics of ASD
- Ensuring functional assessment is administered by practitioners with expertise in ASD
- Recognising that functional needs change across the lifespan and will require reassessment particularly at times of transition for people with ASD.

Key principles include:

- Multidisciplinary assessment of function (as is best practice for diagnostic assessment for ASD)
- An integration, not separation, of diagnostic and functional assessments
- Streamlined processes to ensure that the NDIS avoids the requirement for families and individuals to undergo multiple assessments
- Recognition that that diagnosis may occur at any point in an individual's life and needs to complement the functional assessment process
- Ensuring that there are assessment tools available that are sensitive to the needs of individuals with ASD who have IQ in the typical range.



FURTHER INFORMATION

About the Australian Advisory Board on Autism Spectrum Disorders

The Australian Advisory Board on Autism Spectrum Disorders (AAB ASD) is the national peak body representing the autism spectrum community. Through its members, the Advisory Board represents a significant number of Australian citizens who live with an ASD and who are members of, or who obtain services from, the Advisory Board's member organisations.

The Commonwealth Government's commitment to the development and implementation of an NDIS is a transformational reform process for the disability sector in Australia. A significant increase in funding and a shift to a model of services that gives people with a disability "voice, choice and control" will result in improved life outcomes for people with a disability and their families and is supported by the AAB ASD.

Contacts:

Jon Martin, Chair – 08 8379 6976

Penny Beeston, Deputy Chair - 07 3273 0000

Adrian Ford, Treasurer - 02 8977 8300

www.autismadvisoryboard.org.au

About Autism Spectrum Disorders

Autism Spectrum Disorders are complex neuro-developmental disorders characterised by complex aetiology, variable presentation and widely divergent outcomes. The disorders are defined by the Diagnostic and Statistical Manual of the American Psychiatric Association as pervasive developmental disorders and are characterised by a triad of symptoms: impairments in social interaction; impairments in communication; and restricted interests and repetitive behaviour.

Traditionally, there has been an inadequate appreciation of the size and complexity of the Autism Spectrum community. ASD is more common than Cerebral Palsy, Cystic Fibrosis, Down syndrome, vision impairment and hearing loss combined.

The prevalence is growing at a faster rate than any other disability. The Survey of Disability Ageing and Carers (2009) "showed an estimated 64,600 Australians had autism. This is an increase of 34,200 from the 2003 SDAC, or more than double the prevalence identified in 2003". The Australian prevalence study (2007) indicated a national prevalence rate of 1 in 160 for children aged 6 – 12 years at that time. Further analysis (Buckley, 2009 and Wray, 2011) of additional FaHCSIA/Centrelink data shows steady annual growth in ASD diagnoses from 2004 to 2009 and that National ASD prevalence (for school-aged children) exceeded 1 in 100 (or 1%) in 2009. Some recent data from the US states a prevalence rate of 1:88 (www.cdc.gov/ncbddd/autism/data.html).



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According to SDAC 2009, of people with autism, 74% reported having a profound or severe core activity limitation (that is, they need help or supervision with at least one of the following three activities - mobility, communication or self-care). Autism also correlates with restrictions in participating in the labour force. In SDAC 2009, the labour force participation rate for people with autism was 34%. This compares with 54% labour force participation rate for people with disabilities and 83% for people without disabilities. The ABS also reported that “of people with autism who had finished school, 77% had not completed a post-school qualification, as compared to 50% of all people with a disability and 42% of people without a disability”. These figures are supported by Howlin et al. (2004) in the UK and Taylor and Seltzer (2010) in the US, who found that people with ASD do not successfully transition into higher education, vocational training or employment. A recent systematic review by Howlin and Moss (2012) that found that adults with ASD including those of normal IQ, were significantly disadvantaged regarding employment, social relationships, physical and mental health and quality of life. Similarly, a recent USA study (Shattuck, Narendorf, Cooper, Sterzing, Wagner & Taylor, 2012) found youth with ASD to have significantly lower rates of paid employment than young people with an intellectual disability, learning disability or speech language impairment.

There is undeniable evidence that most people who have an ASD require life time support. Recent research regarding the economic costs, from both the US (Ganz, 2007) and the UK (Knapp, Romeo, & Beecham, 2009) has estimated costs to families of more than \$3 million beyond the ordinary life time costs of raising a child. Compared to other children with specialised needs, children with an ASD are underserved, with more delayed or foregone healthcare, less family centred care, and more difficulties with referrals (Kogan, Strickland, Blumberg, Singh, Perrin, & Van Dyck, 2008). A review conducted by Synergies Economic Consulting (2011) has produced an updated estimate of the annual economic costs of ASD in Australia, including the burden of disease, of between \$8.1 billion (low prevalence) and \$11.2 billion (high prevalence), with a mid-point of \$9.7 billion.

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

A generalist approach will not work in favour of a unique population. The specific and unique needs of people with an ASD and their family's needs to be considered in the context of future funding and service delivery models to reduce the long term social and economic costs to the community. A generalist service model does not provide consistently positive economic and social outcomes for people with ASD. For example, a review of best practice early intervention services for children with ASD has highlighted the need for autism-specific content (Prior & Roberts, 2006). Similarly autism-specific employment services



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have been found to be significantly more effective than generic employment services (Mawhood & Howlin, 1999).

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