

# **Feedback from the Australian Advisory Board on Autism Spectrum Disorders Principles to determine the responsibilities of the NDIS and other service systems**

The Australian Advisory Board on Autism Spectrum Disorders (AABASD) is pleased to have been given the opportunity to provide feedback on the *'Principles to determine the responsibilities of the NDIS and other service systems'*.

Autism Spectrum Disorder (ASD) is a complex, lifelong condition that includes severe social communication impairment and restricted interests and repetitive behaviours that substantially interfere with every-day functioning. People with ASD typically face challenges in all aspects of their life, including early childhood centres, school, tertiary education settings, work, community contexts. They therefore require ongoing support in order to be successfully included in these mainstream settings.

Under National Disability Insurance Scheme Act 2013 (No. 20, 2013) - Section 4 (Point 11), it is stated that reasonable and necessary supports for people with disability should:

- a. support people with disability to pursue their goals and maximise their independence; and
- b. support people with disability to live independently and to be included in the community as fully participating citizens; and
- c. develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment

The AABASD maintains that reasonable and necessary supports for people with ASD must include close and ongoing collaboration between disability support services and mainstream services. We believe that the NDIS should show leadership in improving linkages between disability services and mainstream services, and should take a lead role in the coordination of these services.

We have particular concerns about the following aspects of the document: *Principles to determine the responsibilities of the NDIS and other service systems*.

## **Applied Principles – Mental Health (Page 4)**

There is evidence of extremely high levels of mental health issues among adults who have an ASD. For example, Lugnégard et al. (2011) found 70% of adults with Asperger's Disorder had experienced at least one episode of major depression, and 50% had suffered from recurrent depressive episodes. Similarly, the Autism Spectrum Australia study *'We Belong'* (2012) reported that more than 70% of mainly young adult respondents identified a clinical mental health condition.

In the experience of autism service providers in Australia, mental health services provide limited or inadequate services for people with ASD (Australian Advisory Board of Autism Spectrum Disorders, 2012). People who have an ASD, their families, and mental health service providers themselves, frequently report that services refuse to see people who have an ASD, instead referring them back to the disability sector. This may be because mental health clinicians lack skills and experience in the ASD field or because they attribute the mental health difficulties of people with ASD to their autistic symptoms.

In its recent discussion paper *'The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward'* (AABASD, 2012), the AABASD called for a tiered approach to improve mental health services for people with ASD:

- **Tier 1** provides education and support for universal service providers, early detection and service 'gatekeeper' professionals such as general practitioners, community nurses and school staff. This requires partnerships between specialised disability, health and other sector professionals as appropriate.
- **Tier 2** provides multi-disciplinary collaborative case management input, including the possibility of government, NGO, disability and mental health service partnerships.
- **Tier 3** is the tertiary level of highly specialised service supporting clients with complex needs. This involves a multi-disciplinary, multi-agency collaborative process. Such a resource could be established across mental health, disability and education sectors in each state to "drive" collaborative and innovative approaches.

As there is a complex interplay between the core features of ASD and mental health issues, it is essential that mental health services and the ASD-specific supports offered by the NDIS work collaboratively, with mutual sharing of ASD-specific and mental health specific expertise.

### **Applied Principles: Early Childhood Development (Page 6):**

The comment in relation to the NDIS taking responsibility for 'activities of daily living', but not 'school readiness' does not reflect contemporary best practice principles for early intervention programs for children with disabilities. These principles recommend close collaboration between disability service providers and mainstream early childhood education and care sectors.

A broad range of early intervention services is required in order to provide the foundation of longer-term outcomes including independence and capacity to participate in mainstream life. Depending on the needs of the child, some services may be centre-based, while others provide outreach directly into mainstream kindergartens and child care centres. However, all early intervention services place a strong emphasis on helping the child to make the successful transition to mainstream services. For a child, mainstream life is kindergarten, or school.

Early intervention programs typically aim to help young children overcome barriers associated with their disability. In most cases, underlying impairments associated with their disability (e.g., language, cognitive or motor impairments) impact on a wide range of tasks in multiple contexts. Best practice principles specify that processes should be in place to ensure that skills acquired in disability-specific early intervention are generalised to other settings in which the child needs to perform including school (Prior & Roberts, 2006). As many children with disabilities including ASD have difficulty generalising skills learned in a segregated early intervention setting to other contexts, it is essential to collaborate with professionals in mainstream settings (such as teachers at the child's school) and to help the child develop skills that they will need at school (school readiness).

Mainstream kindergartens, childcare centres and schools would be unable to successfully include children with disabilities such as those with ASD, without support and expertise from ASD-specific early intervention services. For example, a speech pathologist in an autism-specific intervention service will have specialist knowledge of the communication skills of the child and will need to work collaboratively with the teacher to incorporate the child's communication strategies throughout the school day. An arbitrary division of responsibilities between 'activities of daily living' and 'school readiness' as stipulated in the *'Principles to determine the responsibilities of the NDIS and other service systems'* document is unlikely ensure effective inclusion of children with ASD in early childhood services, and therefore is not in the best interests of these children.

### **Applied Principles: School education (Page 7)**

Students with ASD have impairments in social interaction, communication and a tendency for inflexible patterns of thinking and behaviour, and challenges with planning and organisation that impact on their capacity to perform at school. The Australian Bureau of Statistics (2009) found 82% of children with ASD to be 'having difficulty' at school, principally in the areas of learning, communicating and social integration. The behavioural challenges of students with ASD are often misunderstood and mismanaged. For example, they may be distressed by unexpected change, interruptions to narrow interests or obsessions, or sensory overload (Myles & Simpson, 1998). As they lack an understanding of social interactions, they are often vulnerable to social exclusion and bullying (Attwood, 2006). As adolescents become more aware of their inability to "fit in" socially, rates of anxiety and depression increase (Attwood, 2006). A survey of 173 families of children with ASD in mainstream schools by Whitaker (2007) found over 40% of parents to be concerned by the lack of understanding of the reasons for their child's challenging behaviours among school staff.

Evidence suggests that they are significantly more likely than their typically developing peers to be suspended or excluded (Barnard et al., 2000). They are over six times more likely to under-perform academically relative to their level of intelligence (Ashburner, Ziviani & Rodger, 2010).

Parents of students with ASD are more likely than parents of students with other disabilities to resort to home schooling because of serious concerns about their child's unhappiness and the inability of schools to cater for their child's needs (Parsons & Lewis, 2010). Their families may be forced to reduce or abandon paid employment in order to care for these children following suspension or to home school these children. Reduced employment can result in a loss of annual family income (Montes & Halterman, 2008).

The difficulties students with ASD have in being successfully included at school therefore have far-reaching ramifications including:

- inability to fit in socially and being subjected to bullying resulting in increased mental issues in students with ASD
- reduced academic achievement and/or frequent school exclusion leading to reduced capacity to successfully transition into adult roles such as tertiary education and training, and employment
- families forced to abandon employment in order to care or home school their children resulting in a loss of family income and increased mental stress among family members

In view of the complex difficulties experienced by students with ASD, there needs to be close cooperation between services with ASD-specific expertise such as those funded by the NDIS and schools, on a range of issues. This includes sharing of ASD-specific expertise on the impact of the condition on their teaching, learning and social inclusion needs, rather than restricting ASD-specific input to issues pertaining to activities of daily living.

### **Applied principles — higher education and vocational education and training (VET)**

The Australian Bureau of Statistics (2009) found that 77% of people with ASD had not completed a post-school qualification, as compared to 50% of all people with a disability and 42% of people without a disability. A recent Queensland survey (Neary, 2012) found relatively low numbers of young people with high functioning ASD (those with typical range IQ) were accessing a training program, with 26% in full-time training and 19% in part-time training. A large proportion of these young people (28%) had been previously enrolled in a training program but failed to complete it. Parents perceived the barriers to completion of training to include difficulties with organisation, and lack of formal support. There is therefore a need for more ASD-specific support in tertiary education facilities provided by personnel with an understanding of the learning needs of these students.

As is the case with school education, there also needs to be better collaboration between services with ASD-specific expertise such as those funded by the NDIS and Higher Education and Vocational Education and Training Providers. This includes sharing of ASD-specific

expertise on the impact of the condition on their teaching and learning needs, rather than restricting ASD-specific support to issues pertaining to activities of daily living.

### **Applied principles — Employment**

Labour force participation rates for people with ASD are 34%, as compared with 54% for all people with disabilities and 83% for people without disabilities (Australian Bureau of Statistics, 2009). Recent Australian studies have found the level of unemployment among people with high functioning ASD to be around 45-50% (Autism Spectrum Australia, 2012; Neary, 2012). Of those who were employed, the majority had unskilled jobs. More than 50% of Queensland parents of young adults with ASD reported that their adult son or daughter was dissatisfied with his or her employment status, while 85% of parents perceived their sons and daughters as capable of higher level employment (Neary, 2012). Their parents perceived the main barriers to gaining employment to be poor social skills (31%) and poor interview skills (30%). Although many people with ASD have attributes that are valued in the workplace (e.g., attention to detail, honesty, reliability, persistence, tolerance for repetitive tasks and punctuality), they are often challenged by the social and communication requirements of employment, particularly during the interview process (Hagner & Cooney, 2005; Higgins et al., 2008). They are likely to need support in the following key stages of gaining and maintaining employment (Higgins et al. 2008; Mawhood & Howlin, 1999):

- Career exploration
- Training and support in job seeking e.g., interview skills practice
- A thorough analysis of a potential jobs to match job requirements to skills and abilities
- Job coaching/support
- Advocacy to employers regarding the benefits of hiring people with ASD
- Training in work-related social skills

Research suggests that ASD-specific employment support yields better outcomes than generic employment services. An ASD-specific service in the UK achieved a 63% rate of successful job placements as compared to a 25% success rate achieved by generic services for a matched group of adults with ASD (Mawhood & Howlin, 1999).

The AABASD supports Point 5 under the heading Employment which states:

*The NDIS will be responsible for individualised assistance to support a person with disability to **transition into employment**, where these support needs are additional to the needs of all Australians and specifically required as a result of a person's functional impairment, such as training on dress, workplace relationships, communication skills, punctuality and attendance, and travelling to and from work.*

However, in addition to individualised support for transition into employment, we believe that services should include on-the-job coaching/support, to ensure that the person with ASD maintains their employment after having secured a job.

### **Applied principles — Justice**

While the vast majority of people with ASD are law abiding, a small proportion may come to the attention of the criminal justice system, often due to a mental health illness. Clinical experience suggests that a substantial number of such contacts occur because the person's behaviour and its intent are misunderstood. For example, because of a desire to please and/or communication difficulties, a person who has an ASD may confess to criminal behaviour which they did not commit (National Autistic Society, 2011 and 2012). To ensure judicial fairness, all levels of the criminal justice system from police to courts need access to autism support (National Autistic Society, 2012).

The AADASD supports the following points under the heading Applied Principles - Justice:

- *The NDIS will continue to fund the full range of supports related to the impact of a person's disability in a person's support package where the person is not serving a custodial sentence or other custodial order imposed by a court. As such the NDIS would fund supports where the person is on remand or a community based order which places controls on the person to manage risks to the individual or the community (except in the case of secure mental health facilities).*
- *The NDIS will fund specialised supports to assist people with disability to live independently in the community, including supports delivered in custodial settings aimed at improving transitions from custodial settings to the community, where these supports are required as a result of a person's functional impairment and additional to supports required by all Australians in similar custodial settings.*

As indicated in their recent paper '*The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward Discussion Paper*', the AABASD advocates the establishment of local on-call Autism Response Teams by relevant government departments (such as the Attorney-General's Department). Such teams may include a family member working with relevant professional support, such as a social worker, speech pathologist or psychologist who has specialist ASD expertise.

In summary, the AABASD calls for improved linkages between disability services and the full range of mainstream services, and improved coordination of these services.

**Penny Beeston 0438288309**

**Chair**

**Australian Advisory Board on Autism Spectrum Disorders 26 May 2013**

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