



Disability Care and Support

Response to the Productivity Commission's Draft Report April 2011

About the Australian Advisory Board on Autism Spectrum Disorders

The Australian Advisory Board on Autism Spectrum Disorders is the national peak body representing people who have an autism spectrum disorder (ASD), their families, carers and helpers. 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.

Introduction

The Productivity Commission has rightly identified that the disability system is in need of reform. The Australian Advisory Board on Autism Spectrum Disorders supports a commitment to transformational change for the disability sector and the broader community that ensures:

- The creation of an inclusive community that recognises and values the rights of citizenship
- Visionary leadership to ensure the achievement of fulfilling lives
- A simple and transparent system that enables participation and innovation.

It is critical that the intended scheme as proposed by the Productivity Commission achieves the following objectives:

- Recognises and understands ASD as a distinct disability
- Provides a framework for National and State efforts to improve the quality of life of people living with an ASD, reduce the cost of those conditions, and reduce the impact on individuals, their carers and communities
- Informs practice regarding the range of interventions available and responsiveness of individuals to interventions by establishing an evidence base
- Investigates the potential for rationalisation of resources in ensuring a focus on efficient use of evidence based approaches
- Ensures greater access to, and intensity of, a range of evidence based interventions as well as streamlining of service delivery
- Promotes better outcomes for economic and social participation for people with ASD
- Gathers accurate data that assists in guiding policy decision at a Federal and State level
- Develops a partnerships and service regime that delivers a comprehensive, unified and person centred program for each individual with ASD
- Substantially increases capacity and sustainability to deliver appropriate developmental and support programs for people with ASD.

People with an ASD have unique social, cognitive and perceptual difficulties that affect how they experience, understand and interact with the world. They



have a specific characteristic triad of impairments in social, communication and behavioural domains. 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. As such, it is critical that the proposed NDIS will ensure a recognition and appreciation of the unique characteristics of ASD within all stages and elements of design and development.

Comments on the Draft Report

1. Eligibility

The “Tiered” approach proposed will provide clarity on access and eligibility at a National level. There remain several significant concerns from the perspective of the Australian Advisory Board on Autism Spectrum Disorders:

- Autism Spectrum Disorders are complex neuro-developmental disorders characterised by complex aetiology, variable presentation and widely divergent outcomes. **The unique characteristics of ASD will need to be considered within each tier to ensure that families and individuals experience a service response that is sensitive to their unique needs.**
- There needs to be greater clarity on the eligibility parameters for Tier 3. All Autism Spectrum Disorders are characterised by significant impairments in communication and socialisation, and restricted and repetitive patterns of interest and activity. The disorders are described as “*pervasive*” as they affect many areas of the person’s functioning including socialisation, cognition, communication and behaviour. **By definition, people with ASD, have a severe or profound disability. It is unclear how this relates to a “significant core activity limitation” and eligibility for Tier 3.**
- In a report based on data from the 2005 Carer Allowance payment made through Centrelink, MacDermott et al (2006) concluded that there is an estimated prevalence of Autism Spectrum Disorders across Australia of 62.5 per 10,000 for 6-12 year old children. Subsequently Buckley (2009) reviewed Centrelink data for the period 2003 through to 2009. Findings indicate that the prevalence of ASD has increased. Centrelink data from 2009 indicates that the prevalence in 6-12 year olds is 110.85 per 10,000 or 1 in 90 children of that age. This indicates a 1.7 times increase in prevalence in the last 3.5 years (Buckley, 2009). **The new funding mechanism needs to be developed and established to respond to the growing prevalence of ASD and to ensure equitable and sustainable funding.**
- A recent report (AIHW, 2009) describes that ASD is associated with high prevalence of multiple disabilities. In particular, of individuals identified as having autism as their major disability, 58% also reported a psychiatric disability and 38% also reported a sensory/speech



disability. **The eligibility issue of co-morbidity must be well addressed within the scheme.**

- A diagnosis of an ASD may occur at various ages across the lifespan. Within the recommended tier structure, the Commission sees early intervention as encompassing the interventions that may be necessary in the first years of life, when a disability first arises, or around specific transition points such as leaving school or home, or entering the workforce. **It is not clear that eligibility for people with ASD for “early intervention” is available across the lifespan in relation to when the diagnosis occurs.**
- The draft report makes specific reference to all people with an intellectual disability being eligible for Tier 3 services. 75% of people with autism have a co-existing intellectual disability. Having a diagnosis of Asperger syndrome (part of the autism spectrum of disorders) precludes a diagnosis of intellectual disability. However, many of these individuals have extremely complex and challenging behaviours. Essentially, the inclusion of intellectual disability within Tier 3 will create a conflict in eligibility and access for people with a diagnosis of an ASD. This is a situation which already creates a high degree of tension within State jurisdictions. **The issue of including all people with an intellectual disability within Tier 3 is contentious and should be reconsidered.**
- The move towards a model of person centred approaches is agreed. However, the specific and support needs of the family unit must be considered. This is especially the case in ASD where there is a proven genetic link and situations of multiple diagnoses within the family. **The draft report does not provide adequate detail on family support functions that will be funded.**
- There is concern about the possible magnitude of the gap between receiving ‘information and referral services’ under Tier 2 and significant supports under Tier 3. The specific design of the system will need to address this issue. The nature of ASD results in the requirement for supports to be flexible and responsive to fluctuating and episodic needs. **There must be ease of movement between Tier 2 and Tier 3 as needs change. A “safety net” support should be investigated for Tier 2 to allow rapid response to short term increased needs.**

2. Services and Supports

The proposed list of suggested supports is comprehensive. There is undeniable evidence that 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).



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).

The specific and unique needs of people with an ASD and their families 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.

There is a specific need to ensure an effective interface between the disability sector and health (in particular, mental health) to ensure a streamlined and comprehensive approach for people with ASD and co-morbid mental health issues. Anxiety disorders, bipolar disorder, gastrointestinal difficulties, obsessive-compulsive disorder, intellectual disability, epilepsy, Tourette's syndrome, sensory difficulties and specific learning disabilities are all conditions that can co-exist with ASD. A recent report (AIHW, 2009) also describes that ASD is associated with high prevalence of multiple disabilities. In particular, of individuals identified as having autism as their major disability, 58% also reported a psychiatric disability and 38% also reported a sensory/speech disability.

There is a need to develop specific services catering for the needs of people that have a dual diagnosis of an ASD and mental health difficulties. A dual funding model across disability and health may facilitate a better whole of life approach to support an individual.

Extensive research has been undertaken in the field of ASD to determine best practice guidelines for early intervention. **Research should inform the establishment of service delivery benchmarks and funding benchmarks for people with ASD.**

There is a perception that the draft report tends to focus on attendant care needs for people with physical and multiple disabilities. **Specific consideration should be given to the range of supports and therapeutic interventions required to support the complex behaviour needs and developmental needs of people with an ASD.**

There has been a noted increase in the number of people with an ASD interacting with justice systems. **There is a need to develop an effective interface between the justice and disability systems to ensure the effective support of people with an ASD who demonstrate risk-taking or illegal behaviour.**



People with ASD are adults for much longer than they are children and require services and support that will maintain the progress made during their childhood years (assuming diagnosis and service eligibility was determined in early childhood). Without appropriate supports adults with ASD are at high risk of developing co-morbid mental and physical health issues. The human and financial costs associated with family breakdown and dysfunction increases significantly if the needs of adults with ASD are not addressed. **The NDIS should result in an improved range of services for all adults with an ASD delivered by people with relevant expertise.**

The value of ASD-specific employment services must be recognised and such services must be developed and expanded. There is also a need to ensure capability and capacity building of the job network system and the Disability Employment Network through a targeted strategy of awareness, training and the provision of ASD consultancy services. Further, the engagement of the education sector in planning and support for transition to employment is critical as are planned transition programs. For people with an ASD, such transition support should be long term and proactive, commencing in the education setting and continuing through to employment placement support. Finally, social enterprises that focus on business activities maximizing the specialist skills of people on the autism spectrum should be investigated. Supporting increased employment participation by people with ASD and their carers would deliver major economic benefits to Australian society and rewards for individuals. **It is noted that the Commission will seek further clarity around the role of specialist employment services.**

The provision of effective family support is a proactive strategy that decreases the likelihood of family breakdown, preventing progression to more expensive crisis responses. It improves quality of life outcomes for both families and individuals. Community awareness, knowledge and understanding is also improved. Recent research (Sawyer et al, 2010) showed that, for mothers of children with autism, there is a significant relationship between the level of maternal mental health problems and both maternal social support and experience of time pressure. There was also a significant relationship between the level of children's behaviour problems and the level of maternal depressive symptoms. **The development of a comprehensive and integrated system of providing support to families is required.**

The experience of the Australian Advisory Board on Autism Spectrum Disorders indicates that the commonly expressed needs for family support relate to:

- The availability of timely and affordable early identification and diagnostic services



- Access to a key worker to help families navigate the service system post diagnosis
- An individual service plan developed in consultation with the families with the aim of matching the child's needs and the family's needs and resources to interventions
- Access to immediate interventions as described in the individual plan
- Social support networks including links to parent, peer support and sibling networks
- Access to appropriate and coordinated support services such as respite, personal care services, financial assistance and counselling that are flexible and responsive to the family's needs
- Transition plan and key worker support for each transition phase
- Positive behaviour support service (ongoing and crisis specific), across the lifespan to reduce the level of family stress and risk of breakdown and to improve family resilience
- Comprehensive support and education opportunities to empower families to make confident, informed choices, find solutions that suit the needs of their family and secure resources in an efficient and timely manner
- Access to supported employment and accommodation services specific to the needs of people with an ASD.

3. Personalised Approaches

The Australian Advisory Board on Autism Spectrum Disorders supports an approach that recognises and enables service user involvement and participation as a central principle. Families, carers and people with ASD should exercise control over services delivered. Self-directed funding will improve outcomes for people with an ASD. However, there are a number of significant considerations:

Individualised funding models must recognise:

- **Not all families and individuals may want to manage their funding and services**
- **Individuals and families may require assistance to effectively manage services and funding**
- **Individuals and families require access to independent, reliable information about services**
- **Regulatory mechanisms must ensure that only quality services are available**
- **Service providers may require core funding to enable them to manage administrative processes and reporting and accountability requirements**
- **A customised regional and remote response may be required.**



4. Assessment Tools and Processes

International expert opinion views that best practice in the assessment of people who may have an ASD is a comprehensive multi-agency, multi-disciplinary assessment. It is proposed that there must be clear differentiation between assessments undertaken to inform diagnosis and assessments undertaken to inform functional need. However, the two processes are not mutually exclusive. It also needs to be recognised that not all diagnoses will occur in the early years and that diagnosis is a developmental process – that is, the diagnosis may occur over an extended period of time as information is gathered, not as a “one-off” event. Finally, the scheme should allow the flexibility to identify children “at risk” and provide intervention rather than wait for a formal diagnosis. **The NDIS needs to avoid the requirement for families and individuals to undergo multiple assessments.**

Any assessment tools utilised in the scheme must be sensitive to the unique characteristics of ASD and be administered by practitioners with expertise in ASD.

5. Workforce

A high performing workforce equipped with the appropriate knowledge and skills is essential to the delivery of quality services. Successful service delivery relies on the need to recruit, retain and develop staff to achieve both current and future strategic directions. As the fastest growing disability, there is a specific need to address workforce issues to ensure the effective support of people with an ASD.

A strategy is required to ensure effective capacity-building of the workforce resulting in improved expertise and service responses for people with an ASD. Clear industry benchmarks must be established in relation to staff expertise for supporting people with ASD.

6. Governance

The governance arrangements proposed by the Productivity Commission are broadly supported – there is a need for national policy setting and local assessment and decision making. A number of models could achieve this outcome. The principles should be confirmed that ensure a simple entry to the system and sensitivity to the unique needs of people with an ASD.

Many of the member organisations of the Australian Advisory Board on Autism Spectrum Disorders currently perform many of the services proposed for DSOs. These activities should be acknowledged and funded appropriately where that is the desire of an individual and/or their family or carers.

The importance of community capacity building needs greater acknowledgement. Greater awareness and the early identification of



people at risk of developing an ASD can be achieved by engaging the community and professionals through a range of mechanisms including:

- Community Education strategies to ensure greater awareness of the early indicators of ASD and pathways to diagnosis
- Partnerships with Divisions of General Practice and nurses providing home-visiting services and other key stakeholders (eg, mental health sector, justice, teachers and early childhood educators, child care workers)
- Investigating the usage of diagnostic screening tools to be utilised by mainstream and generic services
- Information and communication strategies for families and individuals to encourage self-identification
- Inclusion in the curriculum of undergraduate training for teachers, allied health professionals, criminal justice etc.

Many of the member organisations of the Australian Advisory Board on Autism Spectrum Disorders undertake significant community capacity building activities to ensure greater knowledge, understanding and acceptance of people with ASD. These activities need to be funded.

Summary

The Australian Advisory Board on Autism Spectrum Disorders welcomes the Productivity Commission's draft report on Disability Care and Support. It is envisaged that the proposal for radical reform for disability services will be widely supported and endorsed. It is also envisaged that the reform will result in significantly improved social and economic outcomes for people with an ASD, their carers and supporters. For this to occur, it is critical to recognise that people with ASDs have unique social, cognitive and perceptual difficulties. The proposed NDIS must ensure a recognition and appreciation of the unique characteristics of ASD within all stages and elements of design and development.

Submitted by Jon Martin, Chair

On behalf of the Australian Advisory Board on Autism Spectrum Disorders