AUTISM SA

Submission to the Productivity Commission on Disability Care and Support

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Autism Spectrum Disorders In South Australia

There have been many endeavours in SA to ensure an improved service system for individuals with an ASD. In recent times (2008), attempts have been made via the Council of Australian Governments (COAG) Autism Subgroup to ensure effective interface and synergies between National and State service systems. Further, commencing in August 2008, a number of planning sessions were held with the South Australian Government Department of Families and Communities, Country Health SA, the South Australian Government Department of Health, the South Australian Government Department of Education and Children's Services, the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs and Autism SA to "not only to develop a framework and pathways for ASD services in South Australia but also to determine how these can best complement new Commonwealth-funded initiatives".

Very little progress has been made in improving the service system. There is a clear need for a framework for state-wide services and a clear pathway to access services for people with Autism Spectrum Disorder and their families.

The Key Questions

Who should be eligible?

Autism Spectrum Disorders are complex neuro-developmental disorders characterised by complex aetiology, variable presentation and widely divergent outcomes.

The umbrella term of "Autism Spectrum Disorders" covers a number of pervasive developmental disorders. The American Psychiatric Association (2000) classifies Autism Spectrum Disorders (ASDs) under the broad category of Pervasive Developmental Disorders. Under this definition, ASDs include autistic disorder, Asperger disorder and pervasive developmental disorder - not otherwise specified (PDD-NOS, including atypical autism). 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. The word "*developmental*" is used to indicate that the disorders manifest very early in a person's life and, therefore, affect the course of development.

Key Comments:

- By definition, people with ASD, their families and carers should be eligible for the scheme as having a severe or profound disability.

Who should be in the new scheme and how could they be practically and reliably identified?

Diagnosis is the critical starting point for families to access intervention support services which maximise positive outcomes for both the child and his/her family. This needs to be considered in the development of the scheme.

Key Comments:

- Consistent application of methodology and approach to the diagnosis of ASD is required across Australia
- Access to diagnostic services across Australia should be timely, affordable and accessible irrespective of geographical location. There should be no more than 3 months waiting time for a diagnosis (currently there is up to 24 months waiting list across the states and territories of Australia)
- A national benchmark for a multi-disciplinary diagnostic process should be established
- Medicare rebates should be available for diagnosis at any age (currently available up to the age of 13 years).

Which groups are most in need of additional support and help?

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 ASDs has increased. From Centrelink data from 2009 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).

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. In addition, the Australian Institute of Health and Welfare (2008, 2) reported that:

- “A rise in the reported prevalence rates of disabling conditions associated with childhood such as attention deficit hyperactivity disorder and autism-related disorders resulted in a substantial increase in the reported number of children with a disability in the past decade”
- “Among people with severe or profound limitation, the largest rates of increase were reported for migraine, osteoporosis, autism-related disorders, depression, hypertension, diabetes and cancer”.

In addition to growing prevalence, little is known regarding the long-term life outcomes for people with ASD in Australia. However, what is known is that ASD is a severe and pervasive disorder (as defined in the DSM IV). Current evidence indicates that the outcomes observed for economic and social participation are poor

(National Autistic Society, 2002 and 2008). As such, people with ASD should be considered a significant and priority group for the scheme.

Key Comments:

- The scheme must accommodate the growing population of people with Autism Spectrum Disorders
- The scheme must recognise and accommodate the complex issues of co morbidity in relation to people with an Autism Spectrum Disorder
- Such an identified increase in prevalence is important and can not be easily explained. More comprehensive data and nationally consistent quality data is required to explain State/Territory variations and the national trend
- There would be significant value in establishing a National ASD Register to provide quality data
- That the capabilities for economic and social participation are maximised for people with ASD. With the correct support, great outcomes can be achieved.

What can be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

Key Comments:

- Service access and eligibility must be legislated utilising a rights-based approach based on the UN Convention of the Rights of People with a Disability
- A functional needs assessment should be used to determine eligibility. Such an assessment must be sensitive to the specific and unique needs of people with an ASD

How could people with disabilities or their carers have more power to make their own decisions?

Key Comments:

- National standards regarding the rights and responsibilities of people with disabilities and their carers should be developed in relation to the scheme.

How should the amount of financial support and service entitlements of people be decided?

Key Comments:

- Any model needs to be publicly accountable and reportable

What services are needed and how should they be delivered?

The Autism SA Call to Action (2009) specifies a number of key priorities for service development:

1. Early intervention services that are governed by the following principles:
    - That every child has access to a minimum 20 hours of support per week.
    - That there is a waiting period of no more than 3 months between diagnosis and service provision.

- That equitable access is provided for all children with special consideration given to families in rural and remote regions.

This is a critical priority for the following reasons:
- All research to date demonstrates that early intervention leads to better outcomes for children with an Autism Spectrum Disorder
- There are a number of significant stressors that impact on both the family and individual that are exacerbated by an unresponsive service system
- Sustainable positive outcomes are achieved by providing effective support in the early years.

The Helping Children with Autism initiative has seen great progress made in this area and this comprehensive package of support needs to be continued and expanded. It is important to note that The Senate Standing Committee on Community Affairs (February 2007) recommends that the next Commonwealth State Territory Disability Agreement includes a commitment of additional funding for early intervention.

2. A comprehensive and integrated system of providing support to families governed by the following principles:
    - That families have access to a range of models for support.
    - That the models of support are flexible and responsive to the needs of families.
    - That specific services be targeted at meeting the needs of siblings of a person with an Autism Spectrum Disorder.
    - That generic services be adequately informed and educated to provide appropriate support.

    This is a critical priority for the following reasons:
    - This 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 improved.

3. Services and support to enable adults with an Autism Spectrum Disorder to live independently governed by the following principles:
    - That adults with ASD receive services and support from professionals with appropriate training in autism and related needs
    - That adults with ASD be given every opportunity to have a full and rewarding life by being as much part of the community as they possibly can be
    - That adults with ASD be given every opportunity to be part of the work force
    - That specialised models for long and short term accommodation services be designed to meet the specific needs of adults with ASD; and

- That adults with ASD who have a dual diagnosis have access to community, health, mental health and related services and support as required.

For South Australia, this is a critical priority for the following reasons:

- Over the next ten years the diagnosed adult population will grow by as much as three hundred percent
- The services in place now fall drastically short of meeting the needs of adults.
- Adults with an Autism Spectrum Disorder want to be involved in the planning of services in order to positively contribute towards promoting their own wellbeing and connectedness to society.
- Proactive planning for services is required to avoid a social crisis resulting from unmet need in the community.
- Adults with an Autism Spectrum Disorder are in need of support with Communication, Sexuality, Accommodation, Crisis Management, Education, Criminal Justice, Employment, Socialisation, Healthcare and Advocacy.
- There is no comprehensive service delivery model in South Australia to support the needs of adults with an Autism Spectrum Disorder.
- 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 ignored
- research from overseas indicates that only 3% of adults with ASD are living independently in the community (Barnard et al, 2001)

4. We call for educational services for school aged children with an ASD that are governed by the following principles:
   - That every child has access to a responsive educational service appropriate to his/her needs
   - That educational services are based on sound evidence and quality indicators
   - That there should be a range of educational services for children with an Autism Spectrum Disorder from specialised autism-specific programs to mainstream programs with appropriate adjustments
   - That there be a waiting period of no more than six months between application for an educational service and enrolment.

   This is a critical priority for the following reasons:
   - Research indicates that positive outcomes are achieved by the provision of appropriate educational services related to the needs of children with an Autism Spectrum Disorder
   - There is an increase in the number of children diagnosed with an Autism Spectrum Disorder that require specialised educational support

- There is a lack of educational programs and services that support the needs of children with Autism Spectrum Disorder
- There are high rates of exclusions, suspensions and part time schooling for children with Autism Spectrum which, in turn, creates broader implications for the disability support system.

The Australian Advisory Board on Autism Spectrum Disorders provides further information on service priorities at http://www.autismaus.com.au/uploads/pdfs/Autism_NationalCalltoAction_Oct07.pdf

How could the ways in which services are delivered — including their coordination, costs, timeliness and innovation — be improved?

Key Comments:

- Research consistently provides evidence that effective intervention for people with ASD requires the application of expertise in ASD
- There needs to be clear lead agencies at both a State/territory level and at a national level for the provision of ASD specific expertise and service delivery
- The role of State/Territory Governments in service delivery needs to be reviewed.

Are there ways of intervening early to get improved outcomes over people's lifetimes? How would this be done?

It has already been recognised by the Australian Government that early diagnosis and early intervention is critical through the establishment of the Helping Children with Autism package. All research evidence indicates that early intervention leads to improved outcomes and contributes to improved social and economic participation.

Periods of transition to post school options is also a critical period. Ensuring successful employment outcomes for people on the Autism Spectrum requires a range of strategies.

Key Comments:

- The expansion and development of ASD specific employment services is critical. 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
- 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.
- Social enterprises that focus on business activities maximising the specialist skills of people on the Autism Spectrum should be investigated.

How could a new scheme encourage the full participation by people with disability and their carers in the community and work?

A study by Mawhood and Howlin (1999) found that a specialist supported employment service for people with autism and Asperger syndrome resulted in significantly higher rates of employment than generic disability employment services.

ASD-specific job design and supervision strategies have been found to be essential and this is supported by the outcome rate achieved by ASD specialist DEN Providers funded by the Department of Employment, Education and Workplace Relations.

The Department of Education, Employment and Workplace Relations Report (2007) found that job seekers with ASD had the highest consistent outcome rate of 55% - 65% and a job placement rate of 75% when supported by an ASD specialist DEN provider.

Jobseekers with ASD have specific barriers to sourcing employment, attending interviews, responding to social and physical work environments and scoping work tasks. Employment support that is underpinned by specialist knowledge and expertise is essential if job seekers with ASD are to achieve work participation.

Even though job seekers with ASD have the greatest capacity to achieve employment milestones, the Case Based Funding Trial found that this group took the longest to reach these milestones. This suggests that this population will require a longer period of support from specialized services in order to achieve sustainable outcomes.

Key Comments:

- People with ASD respond best where services are tailored to their unique learning style and where support staff are specifically trained to support people with an ASD.

How can a new system ensure that any good aspects of current approaches are preserved?

No Comments

What should be done in rural and remote areas where it is harder to get services?

Key Comments:

- Increased use of ICT
- Application of a rural and remote loading to funding allocations.
- Comprehensive workforce development strategy.

How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?

Key Comments:

- Improved bureaucratic arrangements through streamlining the National Disability Service Agreement and the roles of Commonwealth and State Governments in different aspects of the service system
- The role of State governments in service delivery also is an issue requiring national resolution and consistency.

How should a new scheme be financed?

The obvious options are via a tax/levy or through general revenue.

How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future?

Economic modelling using accurate data is critical. There are many proposals regarding the potential cost of ASD in the community. For example, Synergies Economic Consulting (2007) produced a preliminary estimate of the annual economic costs of Autism Spectrum Disorder (ASD) in Australia of between $4.5 billion and $7 billion.

Key Comments:

Accurate and comprehensive data is required to inform policy decision and resource allocation.

What are your views about the 'nitty gritty' aspects of a scheme that will make it work practically?

Consumer involvement and participation should be a central principle.

The focus should be not simply on a sustainable funding model but a "service improvement framework" that provides a blueprint for national and state efforts to:

- improve the quality of life of people living with ASDs, reduce the cost of those conditions, and reduce the impact on individuals, their carers and communities
- inform practice regarding the range of interventions available and responsiveness of individuals to interventions by establishing an evidence base
- rationalise resources by ensuring a focus on efficient use of evidence based approaches, streamlining service delivery and creating efficiencies
- assist in guiding policy decision at a Federal and State level
- align with the National Disability Strategy and recognise and understand ASD as a distinct disability with substantial needs of its own
- develop a partnership and service regime that delivers a comprehensive, unified and person centred program for each individual from the disability, health and education sectors
- substantially increases capacity and sustainability to deliver appropriate developmental and support programs for people with ASD.

How long would be needed to start a new scheme, and what should happen in the interim?

No comments