



AUTISM ASPERGER ACT

Submission to the Productivity Commission Inquiry into Disability Care and Support

Introduction

This submission focuses on the care, support and educational needs of Australians who are diagnosed with an Autism Spectrum Disorders (ASDs).

ASDs include three disorders that are defined in the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (known as the DSM-IV). The three disorders that are usually referred to as ASDs are Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder not otherwise specified (PDD-NOS).

ASDs are a distinct disability type: they are not a subgroup of intellectual disability or brain injury. These disorders all involve "severe and pervasive impairment". None of these disorders are "a mild form of autism" though journalists, politicians and bureaucrats frequently describe them that way.

The DSM-IV says few people with Autistic Disorder go on to live independently. Outcomes for Asperger's syndrome and Pervasive Developmental Disorder Not Otherwise Specified are not well known.

ASDs were once considered rare. Now, over 1% of Australian school students are diagnosed with an ASD. The number of children diagnosed has more than doubled every five years for the last 20-30 years. This rate of increase should be a major concern for all Australian Governments, federal and state/territory.

Who we are

Autism Asperger ACT (AAACT) is a not-for-profit community organisation representing over 250 families in the Canberra region, all of whom have family member with an Autism Spectrum Disorder (ASD). Autism Asperger ACT, albeit under a different name, was established in the late 1960s by a group of concerned parents.

Like thousands of other families across Australia, ACT families who have a member with an ASD have grave concerns about the services available for people with ASDs across their life span.

Mission

Actions improving the *quality of life* of people with Autism Spectrum Disorders, their families and carers.

Committed actions

Autism Asperger ACT is committed to:

1. Ensuring that people with Autism Spectrum Disorders can access services that meet their specific needs.
2. Advocating for the rights of people with Autism Spectrum Disorders.
3. Developing awareness and understanding of Autism Spectrum Disorders in the community.
4. Supporting people with Autism Spectrum Disorders, their families and carers.

Our Core Beliefs

1. Australian communities, through their governments, are responsible for ensuring that all people with Autism Spectrum Disorders access adequate and appropriate treatment, rehabilitation, education and training, therapy, support, employment and accommodation throughout their lives.
2. Services for people with Autism Spectrum Disorders should be accessible, appropriate, individualised and of an excellent standard.
3. It is essential that appropriate services are available through all life stages and transitions of people with Autism Spectrum Disorders as Autism Spectrum Disorders are life-long.
4. Services providers should keep up-to-date with and ensure that their services reflect the latest research.
5. People with Autism Spectrum Disorders have the right to be understood and treated with respect.
6. People with Autism Spectrum Disorders need, and deserve, to realize their potentials.

Services offered by Autism Asperger ACT

Autism Asperger ACT has just opened its own office space in the new Chifley Health and Well-Being Community Hub. Prior to this the association operated through the SHOUT offices in Pearce. With our own office space we are able to offer more services to members. The number of meetings and support groups has increased and the library is open longer hours.

Groups coordinated and run by Autism Asperger ACT:

- Monthly meeting with speaker
- Asperger Syndrome Support Group
- Women with Asperger Syndrome and Mothers of Girls with Asperger Syndrome Group
- Parents of school age children support group (day time)
- Parents of school age children support group (evenings)
- Grandparents' Support Group
- Siblings Group
- Social Skills Groups

Question 1.

Who should be the key focus of a new scheme and how they may be practically and reliably identified?

Autism Asperger ACT is strongly of the belief that the new disability scheme should cover both disability present at birth and health conditions which lead to disability. Any disability that is acquired through an accident should only be covered if other forms of compensation are not available. Autism Asperger ACT believes that disability due to the natural process of ageing is outside the remit of the proposed scheme.

Autism Asperger ACT firmly believes that people formally diagnosed with Autism Spectrum Disorders should be included in the proposed new disability scheme. A diagnosis on the Autism Spectrum Disorder (Autistic Disorder, Asperger's Syndrome and Pervasive Developmental Disorder Not Otherwise Specified) is both a practical and reliable process for identifying people who must be included in new and improved services for people with a disability.

Question 2

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

In 2007 Synergies Economic Consulting reported into the economic costs of Autism Spectrum Disorders (ASDs) in Australia. The report concluded that the economic cost was between \$4.5 billion and \$7.2 billion per annum. When this is combined with new data that suggests that the prevalence rate for Autism is doubling every 5 years, Autism Asperger ACT believe that this is one group that needs additional support, both directly in services and indirectly in research funding to find out why the condition is doubling every five years.

Question 3

The kinds of services that particularly need to be increased or created

Given our understanding of disabilities and resources needed for that person for the whole of their life government organizations should be able plan ahead to ensure that the resources needed are available for both the disabled person and their carer.

Early Intervention

The Commonwealth Government advises parents that children with autism spectrum disorders needs at least 20 hours per week for several years of intensive, ASD-specific early intervention therapy. But to date neither the Commonwealth nor the state/territory governments have failed to fully support this.

[http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/\\$File/autbres.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/D9F44B55D7698467CA257280007A98BD/$File/autbres.pdf)

Therapy Services

Therapy services need to be extended so that long waiting lists no longer exist. In the ACT it is easier to obtain regular therapy for preschool rather than school aged children. This is particularly concerning for children who are not diagnosed during their preschool years.

Respite Services across the board like after school care, in home respite, vacation care and flexible respite options.

Currently governments, at both levels, lack ability to put in place long term planning for the needs of people with disabilities.

Work Opportunities

Most people with ASDs experience difficulty in finding work once they have left school. They usually need assistance in learning the expectations of the workplace but once settled they can be excellent employees. They are punctual and conscientious as they focus on their work.

Some people with ASDs are unable to find work in the mainstream environment. They do however require purposeful occupation outside the home. Currently in the ACT carers have to seek out day programs wherever they can. Typically the one person will access Program A for one or two days a week; Program B for half a day etc. If the adult with ASD has not received a government care package the families have to shoulder the costs of these programs.

Appropriate accommodation and living support

Many people with ASDs require supported living arrangements. The ACT government has stated that it will not be opening more group homes which leaves families in dire straits. Many elderly parents are still caring for their adult children while others utilize paid community care options to assist them in the daily supervision and care of their adult children.

Question 4

Ways of achieving early intervention

Essential early intervention could be provided, at little extra cost, by having enlisting the services of professionals who fully understand the need for intensive ASD-specific early intervention. These professionals would design and supervise therapies for individual children.

The majority of the therapy would be provided by therapy technicians working directly with the child. Therapy technicians would be supervised by professionals. "Therapy technician" should be a qualification in its own right (through TAFE) though people training to be allied health professionals or teachers could also be employed after completing the first year of their training.

Question 5

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

Access to intensive ASD-specific early intervention and behaviour support program immediately following a diagnosis of Autism Spectrum Disorder will greatly improve the child's long-term outcome. This in turn will increase the parents' opportunities to be productive, full-time members of the workforce.

Parents need more support particularly during work hours. Having available appropriate after school care, in home respite, school holiday care and flexible respite options that span working hours would increase full participation in the work force.

Question 6

How to give people with disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong)

People with ASDs and their carers need access to information about options available to them and an appropriate funding package to enable them to access these services.

An appeal board consisting of parents/carers as well as professionals and bureaucrats needs to be established.

Question 7

How to improve service delivery — including coordination, costs, timeliness and innovation

Coordination of disability service providers is critical in improving service delivery. Some consideration should also be given to the rationalisation of services to reduce the duplication of administration when many small providers are involved. Service provider peak bodies need to devise an assessment that is suitable and available to all involved providers - this would reduce duplication of assessment and unnecessary paper work.

A national register covering government services (State and Commonwealth), non-government agencies and commercial services would be of great value in (a) ensuring that all appropriate services are considered and (b) in identifying gaps in services from region to region.

Question 8

The factors that affect how much support people get and who decides this

People who have a disability live and their carers are affected by the disability on a full-time permanent basis. Currently carers provide their services for a pittance (\$46 a day if they receive the Carers' Payment, less if they only get the Carers' Allowance). Their payments should reflect the work they do and include the basic entitlements that other workers receive (sick leave, long service, superannuation).

Equally it must be recognised that the people with ASDs are entitled to have their physical, mental and spiritual needs met. They should have the opportunity to be involved in the community like any other person.

The amount of support each person receives needs to be based on how much it would cost to support that disabled individual in an accredited organization on a full time basis.

Question 9

How to ensure that any good aspects of current approaches are preserved

A national forum of peak bodies (carers and service providers) needs to be convened to discuss this issue.

Question 10

What to do in rural and remote areas where it is harder to get services

With the new national broadband network you could have trained professionals remotely supervising Therapy Technicians (see answer to question 4) .

Question 11

Reducing unfairness, so that people with similar levels of need get similar support

By ensuring that every person under goes a complete and comprehensive assessment and those people doing the assessment fully understand the nature and implications of the disability being assessed.

Question 13

How to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future

The whole community must comprehensively finance the proposed new scheme for the care and support of people with disabilities. A Medicare style levy would be the fairest way of raising the necessary funds for this scheme.

Gay von Ess

President
Autism Asperger ACT
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