



A JOINED UP SYSTEM

A MORE INCLUSIVE APPROACH TO SUPPORT
INDIVIDUALS WITH
AUTISM SPECTRUM DISORDERS

CALL TO POLITICAL PARTIES

2010 COMMONWEALTH ELECTION



Executive Summary

In the last 4 years the Commonwealth has taken on a significant lead role in the funding of supports to children with Autism Spectrum Disorders.

Funding of the Helping Children with Autism Package by the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs coupled with funding school based programs through the Department of Education and Training and programs through Playgroups Australia and the Early Days workshops has resulted in the Commonwealth taking on a greater intervention in program supports than has historically been the case.

As a result Government should be congratulated for taking on the issue of enhanced early intervention, parent workshops, establishing Autism Spectrum Disorders playgroups and encouraging greater training and awareness within the education system.

In saying that there is still a great deal to do and responsibility for this rests primarily with State Governments. There is, however, also an opportunity for the Commonwealth to provide both leadership, within a policy framework, and funding of specific program areas historically the domain of the Commonwealth to further enhance outcomes for individuals with Autism Spectrum Disorders. The Commonwealth also has the potential to streamline services at a Commonwealth level and support the development of a more linked up service system.

Driving the need for the position paper is the belief held by Autism Victoria and its members that:

- All people with Autism Spectrum Disorders and their families have a right to a quality service system that supports effective transitions to school and the opportunity to participate fully in adult life.
- A commitment by the Commonwealth to address the failings of the current system to address issues of service delivery and encourage and support a service system in which services are linked one to another.
- A whole of Government and whole of community response is required to ensure individuals with Autism Spectrum Disorder are able to fully engage with the community and achieve Quality of Life outcomes.
- The Commonwealth can ensure that buildings that house Commonwealth services are fully provisioned to assist families through the development of safe areas for children with Autism Spectrum Disorders

This position paper identifies a number of key areas in which the Commonwealth can effect change and ensure the system is more cohesive and potentially easier to navigate.

Introduction

In the last 3 decades the rate of diagnosis of Autism Spectrum Disorders has increased from a rate of 1 in 10,000 to the current estimates of 1 in 100 (Baren-Cohen).

There has also been a recognition within Australia and many other countries that Autism Spectrum Disorders are both complex and challenging with much work still required to fully understand the nature and causes of Autism Spectrum Disorders.

What is also known, however, is that early intervention provides the best long term outcomes and that families supporting an individual with Autism Spectrum Disorder want to have a service system that is seamless and provides for quality of life results. There is a demand by families that a seamless service requires both levels of Government (State and Commonwealth) to present a cohesive and effective service system that aims to be world's best practice.

It is also acknowledged that to date the current service system is anything but seamless and if it is to achieve the level of integration families require, then both levels of Government will need to provide a cohesive and shared approach to service delivery.

It is also recognized that historically, in some states at least, the ability of families to access services has been constrained by the failure of state government to recognize Autism Spectrum Disorders as a disability within the meaning of the various State Disability Acts.

With the stronger engagement by the Commonwealth in the funding of services and in particular the funding of early intervention services and the active lobbying by various State bodies the capacity of Government to support effective outcomes in the early childhood period has been greatly enhanced.

There are however, many areas in which relatively simple and effective actions may have a significant impact on the outcomes for people with an Autism Spectrum Disorder. In some cases these actions are a State challenge while in other areas the action required is at the Commonwealth level.

Respite, Housing and support for Adults to enter and sustain paid employment are examples of key areas requiring a Commonwealth response and this position paper shares the thoughts and concerns of Autism Victoria members. The position paper details recommendations and costings for their implementation Australia wide.

Supporting Early Intervention Services

The current funding initiative for early intervention services has proven to be a major benefit to families and individuals with Autism Spectrum Disorders.

The ability of families to access early intervention has significantly enhanced and encouraged families to seek an early diagnosis and thus early intervention to support the personal development of their children.

The positive outcomes of this program cannot be underestimated and Autism Victoria would encourage Government to not only maintain but enhance the program as a positive initiative to support families.

Recommendation 1

Government commit to the ongoing funding of the early intervention program funded through the Helping Children with Autism package

Investment required: No additional funding (excluding CPI increases).

Autism Victoria would also encourage Government to consider expanding the program to include direct support funding to the parents of children with an Autism Spectrum Disorder. This initiative will allow parents to access a range of supports that will encourage the parents to understand the diagnosis and treatment options more effectively and allow for access to grief counselling.

An effective support program would also potentially impact on and reduce the current levels of marriage breakdown experienced by parents of children with Autism Spectrum Disorders (it is estimated that 80% of families with a child with Autism Spectrum Disorders are sole parent families).

Recommendation 2

Government provide funding to support parents to access services to assist their understanding in the initial stages of diagnosis and service access.

Investment required: \$8 Mil additional recurrent funding

An internal review and survey of families currently in receipt of funding from the Helping Children with Autism initiative has also identified that many families are seeking a greater role from the autism advisors to support effective decision making and service access.

The families have suggested the advisor should be supported to take on a broader role and be a more accessible resource that actively supports families by introducing simple interventions

as a short term measure while parents seek access to professional services. These families then suggest the advisor support the families to navigate the service system more effectively and in a timely manner.

Recommendation 3

The role of the Autism Advisor be expanded to include a brokerage and support role for the period of funding under the Helping Children With Autism program.

Investment required: \$1.1 Mil additional recurrent funding.

Further, many families and many professional practitioners have identified the benefit of intensive speech therapy for young children with Autism Spectrum Disorders. In saying that, it has also been recognised the current level of support for speech therapy and the potential outcomes are compromised by the small number of sessions available. It is considered important that access to additional sessions of speech therapy would have a significant impact for many children with Autism Spectrum Disorders.

Recommendation 4

Government recognise the unique needs of children with Autism Spectrum Disorders and increase access to speech language therapy to a minimum of 20 sessions per calendar year.

Investment required: \$10.2 Mil. recurrent funding

Awareness of rights and options is critical for parents of newly diagnosed children with Autism Spectrum Disorders. Often the medium in which families access and obtain information is via their GP or other medical specialist particularly in these early days of diagnosis. It is essential therefore that GP's and other medical personnel are well informed of the broad range of options available to families particularly eligibility criteria

Recommendation 5

Government to review and develop clear guidelines to support General Medical Practitioners to provide more effective mental health plans. Further within this process awareness programs be conducted to ensure all GP's understand the current eligibility criteria includes children with Autism Spectrum Disorders.

Investment required: \$0.3 Mil. recurrent funding

Respite, Holiday and Before and After School Support

Much has been written about the need for effective support to families caring for a child with Autism Spectrum Disorders or other disability.

The issue of effective support most often highlighted by families of school aged children is the need for respite and more effective and accessible Holiday and Before and After school programs for children with complex and challenging behaviours of concern.

The call for increased access to respite services has been ongoing for many years and successive Governments have either rejected the call by parents and service providers or have not funded the services due to financial constraints. Whatever the reason for the lack of action is it imperative that Government recognise the need for respite and develop and fund an adequate national system of respite services.

Recommendation 6

Adequate funds be provided to Specialist respite services to ensure every family caring for a person with an Autism Spectrum Disorder is entitled to and can access a minimum of 4 weeks respite per annum. As a start point funding be provided for an additional 1,000 families nationally to access 4 weeks respite per annum.

**Investment required: \$11.5 Mil. additional recurrent funding
\$18.0 Mil capital funding**

Likewise, often highlighted by families, is the economic impact of not being able to access effective support for Holiday and Before and After school programs. Limited opportunities have resulted in forcing many families to reduce their working arrangements to only one parent being able to work. This 'forced' decision impacts on a range of family issues not the least of which is the loss of income and thus choice but also the loss or diminished career options for at least one parent.

Recommendation 7

Before and After school and Holiday Programs to be supported and encouraged to develop programs and practices that support the engagement of all children with an Autism Spectrum Disorder.

**Investment required: Before and After Hours – \$36.2 Mil additional recurrent funding
School Holiday program - \$31.0 Mil additional recurrent funding**

Based on 4140 places nationally for:

- Before and After School programs to high needs students and
- School Holiday programs for high needs students

Transition to Adulthood

A critical time for many individuals is the transition from school based learning to higher education, employment and effectively, adulthood.

Issues of attending and participating in higher education, accessing and maintaining employment or even the most basic needs of housing, recreation and social interaction become more complex and challenging for families and carers.

Individuals with Autism Spectrum Disorders can and often are able to work in highly complex and challenging positions. However they are also often socially isolated from their work colleagues, have behaviours that at the least are considered odd, or more often, result in employment termination.

Compounding the behavioural challenges is the lack of awareness or understanding by employers of the many strengths individuals with Autism Spectrum Disorders can bring to the workplace. This lack of awareness not only limits employment options but also creates potential conflicts in the workplace that could have, with greater awareness, been avoided.

Recommendation 8

An ongoing awareness campaign be funded to promote the benefits and opportunities available to employers to encourage a greater take up of employees with Autism Spectrum Disorders.

Investment required: \$2.0 Mil new recurrent funding

Clearly, when a loss of employment occurs, it is not only an economic crisis but a crisis of self esteem and pride. Even where the employment is maintained, the social isolation some people experience can be just as devastating for an individual with an Autism Spectrum Disorder.

It is important to recognise that many people with an Autism Spectrum Disorder could, with minimal support, be gainfully employed in a range of different work places and work contexts.

Recommendation 9

Workplace advisors be funded to support employers and employees to create and maintain a positive and successful work environment. This support may include ongoing workplace education, awareness raising with co-workers and/or advice re strategies to support employees to maintain their employment status.

Investment required: \$13.5 Mil. new recurrent funding

It should also be recognised that many individuals with an Autism Spectrum Disorder could be effective employees where a workplace is specifically developed to address the needs of the workforce.

This may lead to the establishment of an outsourcing organisation that creates employment opportunities for individuals with an Autism Spectrum Disorder by taking on contract work for major providers such as data entry work for the major banks, government departments etc.

This model would ensure the workplace understands and can accommodate the varying needs of each individual whilst providing at the same time a learning environment for transitioning staff into mainstream work place environments.

Recommendation 10

Government fund the establishment of an outsourcing company to bid for contracts for outsourced work.

Investment required: \$1.6 Mil. one off establishment funding

Obviously employment solutions are only one part of the need for adult support. Of equal importance is the need for affordable and accessible housing to be available to individuals who may be on a disability pension or whose employment income is sufficiently limited that affordable and accessible public housing is the only option.

Further compounding the housing issue is the broader area of an ageing carer population and the lack of real housing options for older carers. This issue is not unique to individuals with an Autism Spectrum Disorder but what is relevant is the need for housing that can understand and meet the needs of this unique group of people.

Many people want to live with others who share their values, ideals, opinions and behaviours and this is equally true for people on the Autism Spectrum. It is not acceptable to place a person on the Spectrum into a household which neither understands nor is able to provide a proper home.

There are particular needs that are best met when people with shared values and behaviours are co-located.

Recommendation 11

Through the CSTDA mechanism Government commit to the provision of a minimum of 26 Residential Homes (CRU's) specifically to meet the housing needs of people with an Autism Spectrum Disorder.

Investment required: \$29 Mil. capital investment

Critically over the past decade Australia has experienced significant capital growth in Housing prices. Apart from the issue of affordability which has impacted on the ability of people to purchase property, the increase in housing values has also led to major increases in rental prices.

Whilst private property has undergone significant change, so too has the role of Community Housing organisations. A number of these organisations, historically provided housing for people with a disability via rental affordability policies and practices, are also being transformed into “quasi” entrepreneurial housing developers as government policy drives the Housing Associations to become more focused on a broader catchment group and in essence performing the traditional role of Government as the provider of housing to the most income vulnerable.

Not only is there an increasing number of low income families experiencing rental stress, but this very group is now accessing the rental properties which historically were provided by the Housing Associations for people on welfare. The result is that the housing associations are now providing housing to low income earners at a higher rental rate than could be obtained from people on a disability pension. Thus much of the traditional housing stock that met the needs of people on a disability has now been reallocated to low income earners able to pay higher rental rates.

Recommendation 12

Government provide a 50% increase in the Commonwealth Rental Assistance to people in receipt of the disability pension to assist access to the private rental market, and that CRA be maintained in line with the consumer price index.

Investment required: \$26 Mil. additional recurrent funding

National Disability Insurance Scheme

It has been recognized and acknowledged by successive Governments at both the State and Federal level that the current structure and funding arrangements for an effective and collective approach to the provision of supports to people with a Disability is sadly lacking within the Australian context.

We are a society that prides itself on supporting the most vulnerable and yet we have not been able to provide an appropriate and well resourced support system for the exceptionally vulnerable.

Recommendation: 13

That Government support the implementation of a National Insurance scheme that is funded at a level that ensures all people with a disability are able to achieve Quality of Life outcomes.

Investment required: To be determined by the Productivity Commission

Research, Understanding and External Support

Rates of diagnosis for people with Autism Spectrum Disorders have increased exponentially over the past 3 decades from 1 in 10,000 to current estimates of up to 1 in 100. This may be partially explained by better assessment and diagnosis but this, in itself, is not sufficiently robust enough to explain the growth in diagnosis.

At this stage it is also recognised that assessment and diagnosis rates are continuing to climb and therefore there is an urgent and critical need for significant investment in a broad range of research projects with the aim of increasing our understanding of Autism Spectrum Disorders. Research should not be limited to psychological areas only but encompass a broad range of possible research areas.

Recommendation 14

Significant investment in research funding be made available to research a broad range of areas related to the causes and potential treatment options for, Autism Spectrum Disorders. Establishment of a National Autism Task Force with a five year plan for producing a biomarker based neonatal screening protocol is also recommended in order to provide much earlier intervention than is currently possible owing to the inherent limitations of psychological assessment.

Investment required: \$10 Mil recurrent funding

Compounding the challenge in developing appropriate support structures is the identified lack of rigorous data that is necessary to underpin aspects of a robust support system. At present there is clearly a lack of identifiers to assist in the planning process and this has a significant impact on the ability of the service system to adequately meet the needs of families supporting, and/or individuals with, an Autism Spectrum Disorder.

Targeted and responsive planning requires clear identifiers of need and from a long term structural view, given the increasing diagnosis of Autism Spectrum Disorders, the need for rigorous data collection is essential.

Recommendation 15

Establish a National Register to capture current data, new diagnosis and potential late diagnosis clients on a mandatory basis to assist and inform the planning and provision of service and supports.

Investment required: \$700,000 recurrent funding



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