



WHOLE OF LIFE

A MORE EFFECTIVE SUPPORT SYSTEM
FOR INDIVIDUALS WITH
AUTISM SPECTRUM DISORDERS



CALL TO POLITICAL PARTIES
2010 VICTORIAN STATE ELECTION





EXECUTIVE SUMMARY AND RECOMMENDATIONS

This document outlines the reality for individuals with an Autism Spectrum Disorder and their families. It also clearly articulates and identifies the commitments which Autism Victoria and its members seek from all political parties and candidates considering standing for the 2010 Victorian State election.



The document is based on the current principles of the Autism State Plan and encapsulates the fundamental pre-requisites for achieving the objectives detailed in that document.

Autism Victoria and its members seek an explicit commitment from all candidates to support the recommendations presented in this document and that this commitment extends to ensuring the recommendations will be implemented in the first term of the Government.

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 of life that includes effective early intervention, a positive school experience and the opportunity to participate fully in adult life.*
- *A clear and focused program to redress the inequity and marginalisation, exclusion and disadvantage individuals with Autism Spectrum Disorders have experienced.*
- *State Government is best positioned to ensure planning and investment is targeted at and responding to the needs of individuals with Autism Spectrum Disorders and their families.*
- *A whole of Government and whole of community response is required to ensure individuals with Autism Spectrum Disorders are able to fully engage with the community and achieve Quality of Life outcomes.*



The position paper proposes a strategic and planned approach requiring both significant capital and recurrent expenditure over the life of government and beyond.



It requires a commitment and investment in assisting both individuals with Autism Spectrum Disorders and their families and also increased support and funding to ensure the support system including early intervention services, schools, employment and accommodation services are able to meet the ongoing needs of this unique group of people.

The critical question this raises is "Why invest so heavily in services and supports for this unique group of people?", and the answer is both simple and compelling. All research indicates the sooner and more intense the intervention, the more likely a child with Autism Spectrum Disorder will have in achieving a fulfilling and participatory life.

In simple economic terms research in both the USA by "The Centers for Disease Control and Prevention" and further research in the UK by "K Jarbrink and M Knapp" reveal similar lifetime costs if effective interventions are not supported. In both instances the estimate of life time cost is approximately \$7 Mil. Australian Dollars for both direct support costs, loss of potential income and lost income for one parent to remain at home as the primary carer. This research is further support by The Australian Centre for Autism Services which estimates lifetime costs at \$8Mil. if the child is placed in supported accommodation.



Given that with early and sustained intervention there are real possibilities for many young people with Autism Spectrum Disorders to lead meaningful and independent lives, it is incumbent on Government to invest sufficient resources to achieve this outcome.

SUMMARY OF RECOMMENDATIONS

Recommendation 1

State Government to fund a brokerage, advice and support service for families for effective support from the point of initial diagnosis. This service will be provided as an ongoing service.

Investment required: \$3.25 Mil. new recurrent funding

Recommendation 2

All children be funded, to access early intervention support, similarly to the adult disability sector by the provision of direct funding to families of a minimum of \$10,000 per annum from the time of diagnosis until the age of 8 and successful transition to school.

Investment required: \$16.8 Mil. additional recurrent funding

This is additional funding to existing funding for Early Childhood Intervention services

Recommendation 3

The Early Childhood age and funding eligibility be increased to 8 years of age to support an effective transition process into the school system.

Investment required: Included in costing of Recommendation 2

Recommendation 4

The full range of schooling options be provided to students including the establishment of specialist primary and secondary schools, state wide, that are specifically established to provide positive schooling experiences for students with Autism Spectrum Disorders.

Investment required: To be determined based on need and location

Recommendation 5

All schools inclusive of Catholic and Private, will establish support rooms and/or safe places to support the needs of students with special needs and particularly Autism Spectrum Disorders.

Investment required: \$21 Mil. additional capital expenditure per year over 4 years

Recommendation 6

All schools, including Catholic and Private, be part of a broad and comprehensive Autism Spectrum Disorder initiative including a learning environment audit, assessment and implementation of whole school staff training and development and implement an effective transition process for students entering the school system.

Investment required: \$2.8 Mil. new funding per annum over 4 years.

Recommendation 7

All schools including Special Developmental Schools, Pre-schools and Childcare Centres registered and operating within Victoria to be required to achieve and maintain an accredited service level as part of the key performance indicators for all Senior staff.

Investment required: \$14 Mil of new recurrent funding after implementation of recommendation 6 above

Recommendation 8

The support and transition process to be ongoing throughout the schooling period (both primary and secondary years) and include the provision of brokerage/advice support to parents.

Investment required: \$11.7 Mil. new recurrent funding

Recommendation 9

Funding for individual students be determined within a "support intensity" framework to ensure the support is targeted and ensures the student is able to participate actively in all aspects of the school life.

Investment required: Nil Additional cost
Utilise existing DEECD Disability Support funding.

Recommendation 10

Funding be allocated in line with the Early Childhood funding and be funded directly via the family via a voucher system.

Investment required: Nil



Recommendation 11

All students within the Victorian education system (including Catholic and Private school students) be eligible for access to State funded disability support funding.

Investment required: Nil

Recommendation 12

Schools will allow more flexible approaches and responses with respect to adaptive learning equipment and communication augmentation for students with Autism Spectrum Disorders. For example, body temperature management through flexible clothing options and/or window tinting of buses.

Investment required: Nil

Recommendation 13

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 – \$18.63 Mil additional recurrent funding
School Holiday program - \$15.52 Mil additional recurrent funding

Based on 2070 places for:

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



Recommendation 14

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: \$0.5 Mil new recurrent funding



Recommendation 15

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

Recommendation 16

A QUALITY OF LIFE model be adopted which recognises core quality of life indicators and a SUPPORT NEEDS INTENSITY SCALE be implemented and funded on an individualised basis to support positive life outcomes for people with an Autism Spectrum Disorder.

Investment required: Re-align existing Individualised funding – Nil cost increase



Recommendation 17

State Government fund a rental assistance model that enables people on a disability pension the ability to access rental property.

Investment required: \$26 Mil new recurrent funding

Recommendation 18

The program for home modifications be streamlined and recognise the immediacy of need to support families that require home modifications to maintain the ongoing accommodation needs of their children.

Investment required: \$4 Mil. new recurrent funding

Recommendation 19

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 500 families to access 4 weeks respite per annum.

Investment required: \$4 Mil. additional recurrent funding and \$8 Mil. new capital investment

Recommendation 20

Government commit to the provision of a minimum of 10 metropolitan based Residential Homes and 2 Residential Homes in each Regional area specifically to meet the housing needs of people with an Autism Spectrum Disorder.

Investment required: \$12 Mil. new recurrent funding \$24 Mil. new capital investment

Recommendation 21

A funded model of support to facilitate the ongoing development and maintenance of community support groups be implemented.

Investment required: \$190,000 new recurrent funding

Recommendation 22

Significant investment in research funding be made available to research a broad range of areas related to the causes of, including possible biomarkers and potential treatment options for Autism Spectrum Disorders.

Investment required: \$5 Mil additional recurrent funding

Recommendation 23

Establish a Register to capture current data, new diagnoses and potential late diagnoses clients to assist and inform the planning of service and supports.

Investment required: \$100,000 new recurrent funding

Recommendation 24

Establish a voluntary register, located within the Police Department that is accessible by all emergency services, which contains name, address, photograph and behavioural nuances.

Investment required: \$100,000 new capital/establishment cost only

Recommendation 25

Government amend the current criteria applicable to Aids and Equipment to include the capacity for individuals with an Autism Spectrum Disorder to be able to purchase GPS systems and other means of identification to assist locating individuals with an Autism Spectrum Disorder.

Investment required: Nil cost

Recommendation 26

Autism Victoria to be nominated to be a full member of the Victorian Disability Advisory Council.

Investment required: Nil

**Total Recurrent Investment \$134.09 Mil. per annum.
Total Capital Investment \$45 Mil.**

THE AUTISM STATE PLAN – THE KEY TO EFFECTIVE SUPPORT

The position paper developed by Autism Victoria and the members is based on the Autism State Plan and the principles and priority areas identified through an extensive state wide consultative process.



Principles of the State Plan

- Autism Spectrum Disorders are lifelong conditions. People with these conditions may need a variety of supports throughout their life.
- ASDs include a wide spectrum of disorders. People with an ASD, their family and carers have a diverse range of experiences, skills, strengths and needs.
- Respect for the person, their family and carers, which includes respect for the individual’s culture and dignity at all times.
- People with an ASD, their families and carers have valuable knowledge, experiences and perspectives that should be used in developing services, information and professional development approaches.
- People with an ASD should be able to participate and be included in the types of activities that other people participate in, such as school, leisure and work.
- Support should help people with an ASD reach their full potential; it should also look after the wellbeing of the family and carers.
- People with an ASD, their families and carers should be able to access support. Priority should be given to ensuring disadvantaged individuals do not miss out.
- Support should encourage people with an ASD, their families and carers to speak up, say what they want and make their own choices and decisions.
- Support should be based on sound evidence.



- Priority Area 1** Make it easier to get support
- Priority Area 2** Strengthen the ASD expertise of the workforce
- Priority Area 3** Extend and link key services and support, especially during times of transition
- Priority Area 4** Enhance and provide appropriate educational opportunities
- Priority Area 5** Facilitate successful participation in the community
- Priority Area 6** Develop a robust evidence base about ASD incidence





The challenge is to create an integrated service system that is capable of taking a Whole Of Life and Quality Of Life approach to supporting a person with an Autism Spectrum Disorder



INTRODUCTION

A famous or perhaps infamous politician, depending on your political point of view, was once quoted as saying "Life wasn't meant to be easy".



Although this quote was originally written by George Bernard Shaw (and 'misquoted' by the politician) it could well be a most apt motto for individuals with and families caring for individuals with Autism Spectrum Disorders. The constant demand to demonstrate legitimate need and the difficulty in sourcing funding from the various Government "Silos" makes for a highly stressful and anxious life for many people living with and/or caring for individuals with an Autism Spectrum Disorder.

The compounding issues for individuals with an Autism Spectrum Disorder are also a cause of constant concern and worry for many parents. These unique people often experience higher ratios of Mental Health problems, higher levels of psychopathology, behaviours which might involve the police or courts and challenging behaviours within the family. Further compounding effective responses is a perception that the service support system often lacks a fundamental understanding of Autism Spectrum Disorders and thus the ability to provide effective support strategies¹.



Life for families caring for family members with an Autism Spectrum Disorder is characterised by exceptionally high marriage breakdown (approximately 80% of families are single parent families). Parental mental health problems are significantly greater than for both families with a child with an intellectual disability and the general population. There is a reduced quality of life for the whole family, with damaged relationships within the extended family and social networks often resulting in isolation for adult carers and their children².

The challenge, if these issues and other long standing issues are to be addressed, is to create an integrated service system that is capable of taking a Whole Of Life and Quality Of Life approach to supporting a person with an Autism Spectrum Disorder.

To this end Autism Victoria has consulted with its' members and developed this position paper which provides a framework for the development of an integrated support model which addresses many of the concerns of its members.



1. Life Transitions Problems: Young People and Autism Spectrum Disorders; B. Tonge A. Brereton & K. Bull

2. Life Transitions Problems: Young People and Autism Spectrum Disorders; B Tonge, A Brereton & K Bull

MAKING IT EASIER TO GET SUPPORT

Current research clearly demonstrates that early diagnosis and intervention provides the most effective response and potential for improved quality of life for children with an Autism Spectrum Disorder.

It is also true for many parents, that when the diagnosis is first given, they experience a sense of great loss, overwhelming confusion and devastation. Many parents have reported that at the time of diagnosis they are in shock and will leave the office of the diagnostician armed only with the shock of diagnosis, often commenting that there is little or no support available apart from being given one or two pamphlets providing some information on Autism Spectrum Disorders. Little real guidance or ongoing support in understanding what the next steps are is given.

This creates two major challenges for parents.

1. What do parents do next when their knowledge of the support system is potentially limited and they do not know the pathways to follow.
2. Even when accessing the support system it is reportedly difficult to recognise the best, most appropriate and relevant supports for their child.

This is, for most parents, their first contact with the support system and is often characterised by misunderstandings, confusion and/or misdirection and potentially poor decision making. That can have a profound and life long impact on the well being of their child.

This situation is further exacerbated by many couples who experience immense relationship pressure and the potential breakdown of the relationship. Likewise, many families need to exit one parent from the workforce to adopt the carer role.

Many parents are not or only partially eligible for a Carer's Payment which adds a further economic dimension to the challenge for families.

The cost to an individual with Autism Spectrum Disorder within the context of delayed access to intervention, or inappropriate or non targeted interventions may also result in significant impacts on the individual's ability to reach their potential. Thus the continuing need for higher levels of support throughout their life than would otherwise have been the case.

In response to these realities it is proposed that funding be provided to support families in the initial stages of diagnosis with brokerage and advice in line with the model currently funded through the Helping Children with Autism program via the Commonwealth Government.

It is proposed that this service run in tandem with the Autism Advisor Program but add a more direct and supportive role to families. The role would include the provision of guidance to families through the most appropriate pathways and greater support and advice with regards to intervention options and would support the family through the transition phase as families adjust to their new world.

This is an opportunity for the broker/advisor to share with families a range of strategies that may be helpful during this initial phase and these strategies can act as a short term measure while more focused and targeted funding and intervention responses are being put into place.

At this same time the brokerage and advice service would assist the individual and family to understand and adapt to the diagnosis, deal with their feelings of loss and grief, provide strategies to help maintain relationships and help determine the most appropriate interventions for their child.

Recommendation 1

State Government to fund a brokerage, advice and support service for families for effective support from the point of initial diagnosis. This service will be provided as an ongoing service.

Investment required: \$3.25 Mil. recurrent funding

It is recognised that currently there is a Statewide Early Intervention system available to the child and families although there are extensive waiting times for entry. It is also disappointing to note that there is still limited recognition that a period of intensive autism specific service intervention would greatly benefit many children with an Autism Spectrum Disorder.

Families regularly report that options in terms of both treatment models and length of accessible times are limited, resulting in the potential for shortfalls in choice, continuity and intensity of intervention.

To address this challenge it is recommended the early intervention system be funded at a level that enables the Early Intervention System to provide for greater service provision but also allow parents the option to choose alternative private practice responses if this is considered to be a more appropriate or timely response.

Recommendation 2

All children be funded, to access early intervention support, similarly to the adult disability sector by the provision of direct funding to families of a minimum of \$10,000 per annum from the time of diagnosis until the age of 8 and successful transition to school.

Investment required: \$16.8 Mil. recurrent funding This is additional funding to existing funding for Early Childhood Intervention services.

This funding to be made available to all children diagnosed with an Autism Spectrum Disorder and be based on a voucher system in which parents have the choice of service provider.

This will support the ongoing development and viability of the Early Childhood Intervention service system but will also support the ongoing development of a professional private sector service stream.

The private sector and early childhood system, including pre-schools and childcare centres, would both be subject to an accreditation system that would ensure both quality of service provision but also financial viability of a broader, more extensive early intervention system.



ENHANCE AND PROVIDE APPROPRIATE EDUCATIONAL OPPORTUNITIES

This is often considered the most traumatic and difficult time for both children and parents as the transition period is characterised by a move from a small, highly responsive early childhood system into a broader and more complex school environment.

More generally the transition process can currently be characterised by a short term approach and a lack of funding for expert ongoing support from the early childhood system into a mainstream or specialist school. There is significant knowledge that identifies the importance of effective transitioning and thus the need for potentially an extended period of involvement from the early childhood service system to support the child until at least 8 years of age.

This model of ongoing support would also ensure transition into school is a seamless process.

Recommendation 3

The Early Childhood age and funding eligibility be increased to 8 years of age to support an effective transition process into the school system.

Investment required: [Inclusive of costing of Recommendation 2](#)

There is a strongly supported view, among many parents of school age children with Autism Spectrum Disorders, that there is an ongoing need for specialist schools and in particular autism specific schools to be established. It is acknowledged that there is a critical need for a wide variety of choice in schooling options as some students with Autism Spectrum Disorders may benefit from attendance at a specialist Autism Spectrum Disorder school.

It is further contended that school choices must be available across all ages including primary and secondary school.

It is suggested that the most effective response to this concern would be to develop a school system which recognises the need for a range of transitional and ongoing processes.

Recommendation 4

The full range of schooling options be provided to students including the establishment of specialist primary and secondary schools, state wide, that are specifically established to provide positive schooling experiences for students with Autism Spectrum Disorders.

Investment required: [To be determined based on need and location](#)

Equally there has been significant research that promotes the positive benefits to all parties where a school can provide an integrated school environment in which students of all abilities are successfully included. It is considered critical that every effort therefore be made to ensure the mainstream school system is well resourced and supported to embrace this broad school student population.

In the case of high needs students this may require a school to have a support room, home room and/or safe place. Effectively this implies a school within a school to support the transition process. The benefit of this planned internal support model is that it allows students the opportunity to move between school environments when and if the need arises. This allows the school to respond to the needs of all students in a timely and effective manner and provides a secure and safe environment in which students can flourish whilst still being part of the larger school community.

Recommendation 5

All schools, inclusive of Catholic and Private, will establish support rooms and/or safe places to support the needs of students with special needs and particularly Autism Spectrum Disorders.

Investment required: \$21 Mil. capital expenditure per year over 4 years

Along with the lack of funding for support, many schools are not necessarily fully aware or appreciative of the complex nature of Autism Spectrum Disorders. This can result in inappropriate learning plans, negative behaviours and possible teacher stress. Compounding this situation is the potential increase in stress for the family as the parents also try to deal with an unhappy, distressed or frightened child.

The negative impact can sometimes result in serious misunderstanding within the school system between the parents and school staff and result in the need for conflict resolution meetings. These meetings are often a daunting and disempowering experience for parents. Attending as a sole parent to be confronted by, in many cases, the Principal, Deputy Principal, Special Needs Co-ordinator, Classroom teacher and Regional representative can be overwhelming, not to mention the costs of lost productivity for the school. The family broker/advocate identified earlier in this paper should be an accepted participant of all group meetings at the school.



Recommendation 6

All schools, including Catholic and Private, be part of a broad and comprehensive ASD initiative including learning environment audit, assessment and implementation of whole school community including all staff, students and parents training and development and implement an effective transition process for students entering the school system.

Investment required: \$2.8 Mil. per annum over 4 years.

At the conclusion of the four year period all schools will then be subject to formal accreditation and this demand would become a critical part of senior school staff key performance indicators. Cost of accreditation would form part of the recurrent school costs.



Recommendation 7

All schools including Special Development Schools, Pre-schools and Childcare Centres registered and operating within Victoria to be required to achieve and maintain an accredited service level as part of the key performance indicators for all Senior staff.

Investment required: \$14 Mil. recurrent funding after implementation of recommendation 6 above.



Recommendation 8

The support and transition process to be ongoing throughout the schooling period (both primary and secondary years) and include the provision of brokerage/advice support to parents.

Investment required: \$11.7 Mil. recurrent funding

These strategies to include:

- Prior to enrolment, the broker/advisor meet with parents and, where relevant, support services to determine the most effective classroom and school environment for the child. This discussion may include but not be limited to preferred classroom size, class numbers, appropriate play areas, classroom equipment, the child's learning priorities and the parent/student and school expectations.



- The broker/advisor to then undertake a school “learning environmental” audit to include assessment of school equipment, classroom size, lighting, seating etc, and access to a quiet room as well as suitability of play areas.
- The broker/advisor, in partnership with the whole school staff, to determine their training and support needs. This would include level of knowledge and understanding of ASD and also consider the general school culture including student values etc. From this process the broker/ advisor will, if needed, assist the preparation of a learning and development program incorporating the whole school community with a focus on understanding the importance of a model of Functional Behavioural Analysis and the implementation of positive behaviour support models that benefit all children.
- On an ongoing basis the broker/advisor provide a link and support role for parents and the student throughout their school life. The broker will encourage the development of effective individual learning plans, support staff to develop appropriate behaviour management strategies and act as a resource for teachers and other school staff and students on ASD management and link school staff to a 1300 help line.
- On a term by term basis the broker/advisor to facilitate a review and evaluation meeting with the school and parents to assess the progress in the implementation of the learning plan and to support amendments and/or changes to the plan if required. The plan should include clear roles and responsibilities for all parties.
- At the beginning of term 4 the broker/advisor to facilitate the development and implementation of a transition plan for the student for effective transitions to the next school year. The facilitation process to identify appropriate supports where necessary.
- At the conclusion of the school year the broker/advisor will facilitate a final meeting to review the year and identify any learning that may inform or impact on student outcomes for the following year.

Through the training proposed and the promotion of Functional Behavioural Analysis and the introduction of positive behaviour support models, schools will also be able to address the broad issues of bullying and positive inclusion within the school community. Likewise, the models of problem solving and behaviour management are skills and strategies that are effective for the whole student population not simply children with an ASD. This provides tremendous opportunity for the school system to be a positive learning environment and support the successful inclusion of all students into the mainstream system.

It should also be noted that often parents establish very positive relationships with school staff. Where a school has become “autism aware” the school will have the capacity to also assist families when a possible undiagnosed child is attending the school and the parents are concerned at the behaviour of their child but unaware of the possible causes.

The most positive outcomes for a student, parent and school occurs when all parties feel they are equally respected and heard in the development and implementation of learning plans. The development of these plans will often also mean that students are eligible for support funding based on the level of need as determined by an assessment process.

The major challenge with the assessment process is to ensure the support needs of the child are being appropriately and strategically met. There are often concerns expressed by both parents and schools that the support dollars are limited both in amount and focus and this leads to the potential for the support needs to not be effectively targeted and/or the creation of conflict between schools and parents as to the most effective use of limited funds.

Recommendation 9

Funding for individual students be determined within a "support intensity" framework to ensure the support is targeted and ensures the student is able to participate actively in all aspects of the school life.

Investment required: Nil additional cost.
Utilise existing DEECD disability school support funding



Recommendation 10

Funding be allocated in line with the Early Childhood funding and be funded directly through the family via a voucher system.

Investment required: Nil

At the present time the State Government school funding regime is limited to the State school system which creates pressure on the State system and discriminates against parents who wish to have choice within the available school options of State, Catholic or Private schools. This notion of discrimination should be addressed as a matter of priority.

Recommendation 11

All students within the Victorian education system (including Catholic and Private school students) be eligible for access to State funded disability support funding.

Investment required: Nil

People with Autism Spectrum Disorders may have markedly atypical sensory responses in one or all modalities including vision, hearing, touch, taste, smell and temperature regulation.

This response can be over-sensitive or under-sensitive e.g., a person can fall and have a severe injury but not appear to register pain. Likewise they may not register extreme temperatures and therefore not dress appropriately to keep warm or cool.

They may find strong light worrying or they may not be able to use language effectively to describe such difficulties and subsequent behaviour change may be an indicator of discomfort. Good observation may help recognise difficulties and flexibility in applying rules may accommodate the genuine difficulties.

Inability to regulate body temperature, restrictive clothing and long hours on a bus make for potentially challenging behaviours and although it is recognised that in some case the travel times may not be able to be resolved, some issues can.

Recommendation 12

Schools will allow more flexible approaches and responses with respect to adaptive learning equipment and communication augmentation for students with Autism Spectrum Disorders. For example, body temperature management through flexible clothing options and/or window tinting of buses.

Investment required: Nil

Critical for many families is the ongoing need for both before and after hours school care to enable parents to continue to participate in the workforce. This is both an economic imperative as well as a mental wellbeing imperative for many people and has potential economic impacts that can have long term effects on parents.



Before and after school care programs should be able to accommodate the needs of children with Autism Spectrum Disorder and provide a safe and appropriate environment to support, allow and encourage parents to remain in or return to the workforce once their child has entered school.

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.

Recommendation 13

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 - \$18.63 Mil additional recurrent funding
School Holiday Program - \$15.52 Mil additional recurrent funding

Based on 2070 places for:

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

It is considered critical that as children with special needs enter the secondary schooling system the need for career counselling and employment options be extensively explored and all options, whether further study or employment, be canvassed to ensure the best fit possible.

It is proposed the model developed for the primary school system be replicated for secondary schools and their communities. This would include a comprehensive transition program beginning in year 5 in primary school and through to year 8 in secondary school if required.

Career counselling and the move into further study or employment requires access to highly competent, qualified and knowledgeable career counsellors who are familiar with the challenges facing students with special needs and specifically the challenges of Autism Spectrum Disorders and the workplace. The counsellors should also be aware of the various support arrangements that can be made available to students and the funding systems that support these initiatives.

Whilst this process is undertaken with the student, it is important to promote to the broader community the opportunities for workplaces to have successful transitions of students with an ASD into the workforce.

Recommendation 14

An ongoing awareness campaign be funded to promote the benefits and opportunities available to employers to encourage a greater take-up of employment by people with an ASD.

Investment required: \$.5 Mil recurrent

As with school, successful transitioning to work or further study will often require the input of a person with knowledge and experience of Autism Spectrum Disorder. This person should spend some time with a potential employer and the other employees providing them with insight and support on the best ways to sustain ongoing employment for a person with an Autism Spectrum Disorder. It is also true that this support may be required at other times as issues may arise that could potentially place at risk the employment placement.



It can often be a simple explanation or intervention with fellow employees, employer or the person with an ASD to clear up misunderstanding or conflicts.

Recommendation 15

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 position.



Investment required: \$13.5 Mil. recurrent

Employment and/or further education are important transitional needs for young people exiting schools, however there are considerably more complex needs for adults than simply access to employment or further education.

FACILITATE SUCCESSFUL PARTICIPATION IN THE COMMUNITY

It is certainly true that all people want to achieve a Quality of Life and this is equally true for people with an Autism Spectrum Disorder. However, achieving a good quality of life can be far more problematic for a person with an Autism Spectrum Disorder than for neuro-typical people. The lack of current employment options or support ensures a person on the spectrum is unlikely to find employment and is therefore unlikely to generate sufficient income to participate in society as an equal member.



The lack of income impacts directly on the ability of a person to achieve Quality of Life outcomes on measures such as housing, recreation, social interaction, education physical wellbeing and health. As with the school system it is critical the support necessary for a person to achieve a Quality of Life be based on measurable and appropriate models of support determined by the level of need.

Recommendation 16

A QUALITY OF LIFE model be adopted which recognises core Quality of Life indicators and a SUPPORT NEEDS INTENSITY SCALE be implemented and funded on an individualised basis to support positive life outcomes for people with an Autism Spectrum Disorder.



Investment required: Nil - Re-align existing Individualised funding

Critically over the past decade Victoria 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, which 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 17

State Government fund a rental assistance model that enables people on a disability pension the ability to access rental property.

Investment required: \$26 Mil recurrent

Apart from the critical need to provide support to individuals wishing to access the rental market further housing stress is created for families that wish to maintain support in their home but are faced with a range of challenges including the need to undertake major home modifications at a time of economic stress.

This pressure to modify the home and incur additional expenses is often not possible for some families. Modifications may be required to address structural issues, particularly when a child is identified as an absconder.

There have been a number of recent incidents involving children absconding either from a paid carer or a family member with tragic consequences. Incidents that in some case may have been avoided if the property in which the child was staying had been subject to the necessary modifications.

Recommendation 18

The program for home modifications be streamlined and recognise the immediacy of need to support families that require home modifications to maintain the ongoing accommodation needs of their children.

Investment required: \$4 Mil. recurrent funding

Within the broader area of Disability Services the issue of respite is both ongoing and critical. Much has been written and reported on the level of stress and anxiety experienced by many families that lack the ability to access ongoing and regular respite.

This issue has been raised by advocates and direct service providers for many years and was a key issue leading into the last State election without resolution. Of critical concern for families of children with an Autism Spectrum Disorder is both the need for respite but also respite in Autism Specialist Respite services. Much is written about the specialist needs of the Autism community and this is particularly true of respite. One of the major causes of stress for a person with Autism Spectrum Disorder is the impact change can have on their wellbeing. For this reason it is critical that the respite service understand this reality for young people and that staff have the skills, knowledge and expertise to support young people in respite with Autism Spectrum Disorders.

For this reason specialist services are the preferred model.

Recommendation 19

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 500 families to access 4 weeks respite per annum.

Investment required: \$4 Mil. recurrent and \$8 Mil. capital investment

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 20

Government commit to the provision of a minimum of 10 metropolitan based Residential Homes (CRU's) and 2 Residential Homes (CRU's) in each Regional area specifically to meet the housing needs of people with an Autism Spectrum Disorder.

Investment required: \$12 Mil. recurrent funding \$24 Mil. capital investment

Critical support roles are played by parents that significantly reduce the burden on Government to provide support through the funded support system. Many of these families have established support groups that provide mutual support, information and advice to other support group members and have been of significant benefit to Government in terms of voluntary support services.

Providing ongoing support and enhancing the ability of the support groups to continue to provide and develop additional support structures is a cost effective and efficient way to increase the volunteer support model for families of children with an Autism Spectrum Disorder. Critically, the support groups report that the challenge of establishing and maintaining the support group without external support can lead to support groups folding and the obvious loss of these support mechanisms.

Recommendation 21

A funded model of support to facilitate the ongoing development and maintenance of community support groups be implemented.

Investment required: \$190,000 recurrent



DEVELOP A ROBUST EVIDENCE BASE ABOUT ASD INCIDENCE

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 22

Significant investment in research funding be made available to research a broad range of areas related to the causes of, including possible biomarkers and potential treatment options for Autism Spectrum Disorders.

Investment required: \$5 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 expressions 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 23

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

Investment required: \$100,000 recurrent funding

Many people with an Autism Spectrum Disorder come into contact with the justice system in one form or another. This contact may be due to behaviours of concern that attract the attention of the Police and result in attendance in court and ultimately the prison system. Or it may be more simply that the individual absconds and the police are required to locate the person as soon as possible to avoid harm to the person with Autism Spectrum Disorder.

In either case it is important the Police are both aware of the influences an Autism Spectrum Disorder may have on the person, and that the police also have the skills and a sensitivity to deal with these issues.

To assist in this response there are a number of actions that could be taken to support a more sensitive and targeted response by Police.

Recommendation 24

Establish a voluntary register, located within the Police Department that is accessible by all emergency services, which contains name, address, photograph and behavioural nuances.

Investment required: \$100,000 capital/establishment cost only

Recommendation 25

Government amend the current criteria applicable to Aids and Equipment to include the capacity for individuals with an Autism Spectrum Disorder to be able to purchase GPS systems and other means of identification to assist locating individuals with an Autism Spectrum Disorder.



Investment required: Nil cost

Critical to supporting effective outcomes for individuals with Autism Spectrum Disorders and their families is to have a clear voice on a range of working parties and established Advisory bodies. At this stage Autism Victoria and its members are represented on the Autism State Plan, Quality Frameworks and a number of local advisory groups. For effective representation it is important Autism Victoria also be represented on key, ongoing, advisory disability reference groups.

Recommendation 26

Autism Victoria be nominated to be a full member of the Victorian Disability Advisory Council.



Investment required: Nil

Total Recurrent Investment \$134.09 Mil. per annum.

Total Capital Investment \$45 Mil.



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