

Consultation Paper investigating experiences with Autism Services in SA



Draft Report on Disability Care, Support, Early Intervention, Education, Unemployment, Transport, Accommodation, Health and Aged Care for People with Autism Spectrum Disorder (ASD)

Overview and Recommendations

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INTRODUCTION

The writer of this submission is Rick Neagle who is the father of two (2) children, the youngest a son with autism aged 11. He is also the President of **dignity for disability**.

dignity for disability (d4d) Inc is a not-for-profit incorporated organisation and a political party, whose Board consists of a mix of people with disabilities (PWD's), carers of people with intellectual disabilities and people with a social conscious. d4d is a single issue party, which was founded primarily by a group of people concerned about the increasing unmet of people with intellectual disabilities.

At the last State Election in March 2010, d4d campaigned vigilantly on a range of disability issues and as a result our Legislative Council Candidate, a young woman, the Hon Kelly Vincent MLC was elected by the people of South Australia to the Upper House of the SA Parliament.

The political mantra of the d4d party is a belief in 'a fair go' for everyone. It is a human rights based organisation that aims at ensuring representation in Parliament, in particular for people with disabilities. A unique opportunity exists, to grasp together with strong leadership, to bring the often fractured disability community together, and bring about real change. The goal of d4d is to ensure "**dignity through choice**".

METHODOLOGY

There has been insufficient time for d4d to seek community consultation regarding Autism Spectrum Disorder (ASD) and therefore the views expressed within this submission are those of the writer only. The writer suggests that the State-Wide Autism Project (SWAP) together with Autism SA consider the following; the independent consultant grants d4d a special provision to seek further consultation from its members and the wider community. If accepted, d4d will guarantee a further lodgment of a revised submission on or before 31st January 2012.

NATIONAL DISABILITY INSURANCE SCHEME

The recent announcement by the Gillard Government supporting the implementation of a National Disability Insurance Scheme (NDIS) as recommended by the Productivity Commission in its Final

Report tabled in July 2011 was long overdue. That report acknowledges the following “the disability support ‘system’ overall is inequitable, underfunded, fragmented and inefficient.” Although a few politicians from major parties have raised these issues from time to time, governments of all persuasions, both state and federal, have been unwilling to make significant changes and improvements to disability legislation.

The writer, therefore, congratulates the Productivity Commission on its Final Report, *Disability Care and Support*, handed down on July 31st 2011. For the first time, the Commission has presented a proposal which outlines a realistic and achievable method to provide not only people with ASD but all people with disabilities across Australia with a fair and equitable support system. As a result, the rights and subsequent needs of people with ASD have not been realised over the last few decades. The impact of this is far reaching given that the prevalence of ASD is increasing globally. Current estimates of the incidence of having a child with ASD currently stands at a 1 in 170 chance¹.

There is also a burgeoning growth in the number of families burdened with multiple children with ASD. On occasion, there may be one or both parents who not only have the autism gene but also display autistic tendencies themselves. Furthermore co-morbidity is a common presentation. There is overwhelming evidence that people with ASD are more likely to have a range of mental health issues such as anxiety disorders. Family members burdened with the caring role are also more disposed to depressive disorders thus placing extra stress on family units creating an increased likelihood of marital breakdown and family disunity. The impact of this negatively impacts on the economic productivity of the family unit, the wider community and the overall Gross Domestic Product in Australia.

Uncertainty remains surrounding legislation of the NDIS. In the event that legislation occurs the writer believes that the five (5) year time frame to implement the scheme as recommended by the Productivity Commission is too long of a delay. The delivery of service provisions for persons with ASD is required immediately.

AUTISM COST

A study conducted in April 2011 by Synergies Economic Consulting² shows the total annual cost of ASD to the Australian community is in the order of over eight billion dollars (\$8.1B) low prevalence

¹ Australian Advisory Board on Autism Spectrum Disorders, 2010

² Synergies Economic Consulting; Economic Costs of Autism Spectrum Disorders, 2011

to over eleven billion dollars (\$11.2B) high prevalence each year with a midpoint of approximately ten billion dollars (\$9.7B). The full report bases these figures on the lifespan of each person with ASD that has not had access to early intervention, resulting in the need for lifelong allied health support. The average annual incremental cost equates to eighty seven thousand dollars (\$87K) per person with ASD (based on the midpoint of the assumed prevalence estimates).

EARLY DIAGNOSIS

An early diagnosis of ASD is an urgent priority before the introduction of an early intervention program can occur and a subsequent educational placement can be offered to children with ASD. The most important role of any organisation or body supporting people with ASD is to facilitate this process and then to implement immediate access to a myriad of essential resources. One such organisation is clearly Autism SA.

“Intellects” and/or “experts” in ASD universally recognise that early diagnosis, which can occur before the age of two (2) is essential in order to implement effective early intervention programs and to improve positive outcomes of children with ASD in terms of productivity, independence and socialisation.

EDUCATION

Section 24 of the United Nations Convention of Rights of People with Disabilities clearly states that;

“every person with a disability is entitled to an education without discrimination and on the basis of equal opportunity.”

Therefore it follows that Governments must ensure a life-long inclusive education system is provided to enable children with ASD:

- To develop their mental and physical abilities as well as their personalities, talents and creativity to their fullest potential;
- To develop their sense of dignity and self-worth as fully as possible; and
- To participate as effectively as possible in their community.

The definition of education must extend to the inclusion of early intervention programs for preschool children who require intensive therapies and support. These programs should be provided in addition to normal child care and kindergarten services.

Children with ASD, their families and advocates, must be provided with a choice of primary and secondary schooling placements which meet their varying needs. Choices in education are often difficult because of the limited number of facilities and are often prohibited by the geographic location of these facilities. These specific choices are described on page 15 of this submission.

The culture of tertiary education demands diversity for all adults with ASD, who meet the requirements to attend TAFE or university programs and who wish to do so, by the provision of appropriate and necessary supports. It follows that young adults with ASD opting not to undertake tertiary education, apprenticeships and employment programs should be otherwise assisted in gaining productive employment in either open or sheltered businesses. In the long term this will provide far reaching benefits to the economy by maximising the potential, skill development and ability of people with ASD to assimilate into society. Provision of these employment opportunities are discussed in greater detail on page 19 of this submission.

At all levels of education, professional teachers and other support staff must be provided with complete and adequate training which should include the awareness and use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques, materials and resources to support children and adults with ASD.

Early Intervention

Early Diagnosis is meaningless without the IMMEDIATE provision of Early Intervention programs. Currently there is a panacea of options within the Autism Community in South Australia ranging from Applied Behaviour (ABA), Verbal Behaviour (VBA), Floortime and so on. Many of these programs are accredited and favour some consumers in preference to others. It is noted that there are some non-accredited early intervention programs available to consumers which have varying outcome benefits, and thus their efficacy is questionable.

One example of a multi-disciplinary early intervention model delivered by an accredited service provider is the autism early intervention outcomes unit (AEIOU). This model is favoured by the writer because it has quantifiable outcomes, a strong base of ongoing research and demands a high ongoing quality in service provision. The writer is also respectful that the model remains the intellectual property of the AEIOU Foundation.

Best Practice Guidelines

In 2005, the Hon Chris Pyne³ Federal Member for Sturt, directed an evidence based review and publication of Best Practice Guidelines for early learning for pre-school children with autistic disorder, whilst then the Minister for Health and Aging. These guidelines can be costed, audited against, and represent a minimum entitlement for these children and their families. Preliminary estimates indicate that less than twenty percent (20%) of Australian children with ASD receive an early childhood program that meets these guidelines.

Each year there are around seven hundred and fifty (750) children diagnosed with ASD where funding shortfalls means there are up to five hundred (500) of these children excluded from receiving the many positive benefits of early intervention programs. An unpublished study from Synergy Consulting Economics⁴ proves there is an urgent need for the Federal Government to provide an additional and direct investment of thirty million dollars (\$30M) in funding for early intervention services each year to ensure no child misses out. That same study emphatically states “The incremental cost to government to ensure that no child with autism misses out is small in comparison to the lifetime cost to the community when considering the long term savings.”

A previous study from the United States of America revealed that the average lifetime cost saving for a pre-school child with ASD accessing early intervention is US\$1.5M (AU\$1.2M is a conservative estimate of the cost in Australia). Therefore, for every year of intensive early intervention a child receives, there is about a six hundred thousand dollars (\$600K) cost saving to the broader community over the lifespan of the individual in reduced carer costs as these individuals should become productive members of the community.

These costs to the community include welfare and carer payments, under employment, high health and medical costs, rehabilitation and an increased demand on correctional services and rehabilitation of people with ASD. The writer stresses that our prison and welfare systems are overcrowded with vulnerable people and in particular, People with Intellectual Disabilities (PWID) some of whom have ASD.

³ Report by the Hon Chris Pyne, 2005

[http://www.health.gov.au/internet/main/publishing.nsf/content/846804F6D67F34F3CA257280007853DE/\\$File/autrev.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/846804F6D67F34F3CA257280007853DE/$File/autrev.pdf)

⁴ Synergies Economic Consulting; Economic costs of Autism Spectrum Disorder 2011

The Federal Government⁵ has been a strong advocate for early intervention of children with ASD evident by having funded six (6) Autism Specific Early Learning and Care Centres (ASELCC) across the country in 2009. This provided one hundred and twenty (120) fully funded placements for children with ASD and utilised some of the funding from the Helping Children with Autism package.

The AEIOU Foundation

The AEIOU Foundation⁶ currently operates ten (10) centres around Queensland with a total of two hundred (200) children enrolled, one hundred and thirty (130) staff including twenty (20) therapists and thirty (30) teachers. The centres are located in Brisbane and major Queensland rural centres. Further information is available on their website at www.aeiou.org.au.

The strategic plan of the organisation includes a goal to run pilot rural programs with its joint venture partner Goodstart Early Learning Centres. These programs currently operate in Emerald, Harvey Bay and Bundaberg.

The AEIOU Foundation also runs another pilot integrated program operating out of the University Sunshine Coast. Two (2) other priority regions have been targeted to deliver further services, namely in North Brisbane and the Gold Coast.

The AEIOU Board

The AEIOU Board was founded by Chairman Dr James Morton, a Haemato-Oncologist, 2011 Ernst and Young Social Entrepreneur of the Year and the father of a son with ASD. AEIOU is a not-for-profit organisation whose Board demands a professional and an ongoing entrepreneurial approach.

The current board has a strong mix of well respected and high profile members from the Queensland business and sporting community who have a blend of skills and expertise in accountancy, communications, economics, government Occupational Health and Safety (OHS), health, management, media and legal matters. It offers a multi-disciplinary model of early intervention for children with ASD driven by the private business sector based on positive outcomes and supported by quantitative and qualitative research.

⁵ Education Options for Children with Autism Spectrum Disorder
Ministerial Advisory Committee; Students with Disabilities October, 2010

⁶ autism early intervention outcomes unit (AEIOU) www.aeiou.org.au

The current CEO of the AEIOU Foundation is Mr Alan Smith. He was previously a teacher and has worked in the not-for-profit sector for the last decade. His previous employer was Greening Australia. Alan has a personal motivation to drive change in Federal and State Education and Early Childhood government policy.

Program Structure

Each child that attends the centre(s) on a full time basis receives twenty-five (25) hours of intensive early intervention as well as twenty-five (25) hours of childcare respite which equates to a total of fifty (50) hours of total respite per week for families. In 2011, the AEIOU Foundation will provide a combined total of one hundred and seventy thousand (170 000) hours of early intervention and four hundred thousand (400 000) hours of respite.

The AEIOU structure has implemented an active research program, with ten (10) prospective studies and presented four (4) abstracts at the Asian Pacific Autism Conference (APAC)⁷ and in addition to that, provides a school support program. A partnership exists with the Griffith University to establish an ASD Centre of Excellence with a focus on training teachers to work with children who have been diagnosed with ASD in the classroom. That partnership has facilitated the recent appointment of a Professor of Autism and offers Under-graduate and Post-graduate Diplomas through to Doctorate Degrees within its educational programs.

Outcomes

The Queensland and Commonwealth Governments demand documented evidence of robust data combined with formal ASD assessment to validate the positive outcomes on service delivery by the AEIOU centres. The AEIOU Foundation has collected data that states children with ASD who have less than a ten percent (10%) functional communication on entry to their program gain greater than ninety percent (90%) functional communication on program completion.

Furthermore, AEIOU services are provided to children with ASD who are considered “high needs”, and therefore have a combination of behavioural, non-verbal and sensory issues. Data from this clinical presentation also demonstrated that seventy-five percent (75%) of children with ASD achieve mainstream school transition (based on children with ASD who have an IQ less than twenty percent (20%) expected on program entry).

⁷ Verbal Communication James Morton APAC – Asian Pacific Autism Conference, *West Australia* 2011

Program cost

The cost of the AEIOU program to a family of a child with ASD is \$46 000 per annum for a duration of two (2) years. The Commonwealth Government meets fifty percent (50%) of these costs. The total sum of twenty-three thousand dollars (\$23K) is derived from a combination of Commonwealth rebates up to twenty-two thousand dollars (\$22K) and an additional Carers Allowance/Bonus of three thousand two hundred dollars (\$3.2K). The Commonwealth benefits consist of the Child Care Benefit, Child Care Rebate, Carers Allowance, Carers Supplement and Helping Children with Autism Package.

For a viable early intervention program to exist, it requires commitment from the State Government to match funding from the Commonwealth Government as stipulated within the Commonwealth Disability Services Agreement (CDSA). The Queensland Government is committed to the CDSA and thus the AEIOU model of early intervention runs successfully because it is provided with a further twenty-three thousand dollars (\$23K) of recurrent funding from the State government.

In addition, twenty-five percent (25%) of the families attending AEIOU programs are on incomes of less than forty thousand dollars (\$40K) per annum (under the AEIOU model for families on incomes up to sixty thousand dollars (\$60K) out of pocket costs are covered by the Carers Allowance and bonus). Families of children with ASD in this demographic, thus receive twenty-five (25) hours per week of Best Practice Early Intervention for forty-one (41) weeks per annum from autism trained staff with an adult:child ratio of 1:2. These children therefore receive fifty (50) hours of respite for up to forty-eight (48) weeks per year (that is, a thousand (1000) hours of intensive Early Intervention and two thousand four hundred (2400) hours of professional autism specific respite). This is essential given that thirty-five percent (35%) of families of children with ASD live in poverty.^{8 9 10}

Therefore the potential effect on families accessing the AEIOU early intervention program can ease their overall socio-economic stress. These families are then able to provide more personal care to other family members, reduce their stress levels at home and access employment opportunities otherwise not accessible to improve the economic productivity of their family unit.

⁸ Price Waterhouse Cooper - Economic Reports of OECD countries for People with Disabilities, December 2011

⁹ Price Waterhouse Cooper - Disability expectations investing in a better life, a stronger Australia achieving better outcomes for people with a disability and their families. November 2011

¹⁰ Organisation for Economic Co-operation and Development (OECD). Sickness, Disability and Work: Breaking the Barriers – A Synthesis of Findings across OECD Countries. 2010

Cost benefit analysis of AEIOU Best Practice Early Intervention

As cited previously regarding Best Practice Guidelines on page 8 of this submission, Early Intervention requires a two (2) year commitment to prepare a child for independence making this a six hundred thousand dollars (\$600K) cost savings per year. The overall aim of the AEIOU Foundation is to provide an accredited program so that the majority of children with ASD will achieve independence and enter the workforce thus relieving the national economic burden of autism.

Cost benefit modelling studies delivered by Synergy Economics Consulting are still to be fully completed but initial estimates project that it is likely to be a Return on Investment (ROI) between four times (4x) if the child with ASD gains ten percent (10%) improvement and up to thirty times (30x) if the child with ASD achieves a normal life pathway. So ultimately, the ROI is thirty (30) fold with the support of the State government. This is based on an initial cost of ninety thousand dollars (\$90K) for two (2) years of early intervention. The life time saving associated with a child with ASD attending a mainstream school, working part-time and being independent is around two million dollars (\$2M) with a cost benefit ratio of twenty-five dollars (\$25) for every dollar (\$1) invested into that practice.

That study led to Synergies Economic Consulting lodging a submission to the Productivity Commission¹¹ that indicated that there is an urgent need for the Australian Government to provide an additional and direct investment of thirty million dollars (\$30M) in funding for early intervention services each year to ensure no child misses out.

The AEIOU Foundation believes this is an initial investment that will in turn lead to an improved quality of life and significantly reduce the economic impact on the Australian community by more than one billion dollars (\$1B) a year in the long-term. There will be less need for Allied Health Care and enhanced participation in the long term, because individuals with ASD will have a greater ability to learn important life skills and increase their future prospects in employment opportunities.

The AEIOU Foundation also manages the Queensland-based ASELCC centre in Brisbane as provided by the Federal Government (see page 9). For the purpose of comparison, service delivery of the equivalent ASELCC centre in South Australia is provided by the Anglicare Centre located at Daphne St Prospect. The AEIOU Foundation provides an additional two hundred (200) fulltime placements for children across Queensland which is partially funded by the State Government but needs to raise

¹¹ Productivity Commission report on Disability Services July 2011
<http://www.mdaa.org.au/news/australia.html>

money in order to close a deficit of ten thousand dollars (\$10K) per child, per year under this program.

Proposal to South Australian State Government

As previously mentioned the writer strongly recommends the implementation of a multi-disciplinary model in early intervention such as those services delivered by the AEIOU Foundation. Based on per capita, the South Australia cost would be around five percent (5%) of the total National cost of operating the AEIOU program. Moving forwards with this proposal in South Australia, ultimately depends on what the State Government wants to do. It follows that this proposal is conditional on the assumption that the State Government adopts the AEIOU model of early intervention services.

Capital Expenditure

The AEIOU Foundation would make the capital infrastructure investments. These could be delivered in a timely manner to fit with election cycles in South Australia for the new Premier. An initial capital grant is required to establish an initial hub facility¹² which demands a parcel of land three thousand square metres (3000m²) and a capital cost of two million dollars (\$2M). A commitment of one million dollars (\$1M) in capital has been secured already from a benefactor in South Australia and the AEIOU Foundation will raise the remaining capital.

Recurrent funding provided to AEIOU therapy and educational services need to be located in or near to a tertiary educational institution, so that undergraduate and post graduate teaching and therapy programs can have direct input and access to the AEIOU program structure.

The writer strongly recommends the Flinders University Bedford Park as a preferred site due to its strategic location to the Southern Expressway. Bedford Park is located in the southern metropolitan area of Adelaide and gives potential families from lower socio-economic areas South of Adelaide easy and direct access to an AEIOU facility. Bedford Park also has a vast area of land to establish a facility near the University and ample car park space.

An initial AEIOU centre in the South of Adelaide will then offer similar opportunities to those families who can access the established Anglicare ASELCC located in Prospect, North of the Adelaide City.

¹² A hub facility works on the “hub and spoke” model of service provision. A hub is the central resource facility for children with ASD, their families, their advocates and education teachers to access for their ongoing management and/or care.

Delivery of rural services will occur by travel and real time internet models currently used in the AEIOU rural program developed in Queensland.

Current Placement Need

Current estimates of ASD incidence in Australia are stated on page 5 of this submission. Some experts believe it is more likely in the vicinity of a one to hundred (1:100) ratio¹³. The current need of an early intervention model is one (1) placement/ten thousand (10K) population based on Western Australian (WA) registry data of prevalence of ASD of thirty-eight thousand per ten thousand (38/10K) people and three hundred thousand (300K) children born per annum within a population of twenty-two million (22M). This is currently the only accurate register in existence in Australia.¹⁴

Taking into consideration the Commonwealth Centre of twenty (20) placements and the families who will choose to do home based ABA programs or other early intervention models; there is probably a need for around one hundred (100) additional placements, seventy to eighty (70-80) in Adelaide and twenty to thirty (20-30) in regional areas of South Australia.

Recurrent Funding

Based on the program cost of forty-six thousand dollars (\$46K) described under the AEIOU funding model, the writer proposes that the State government announces a recurrent grant of two and half million dollars (\$2.5M) per annum for four (4) years to develop one hundred (100) placements around South Australia.

The AEIOU Foundation would eventually develop seventy to eighty (70-80) placements in Adelaide operating from two (2) centres and a regional network of twenty to thirty (20-30) placements by partnering with local childcare providers. It is worth noting that the Queensland grant for two and a half million dollars (\$2.5M) per annum for five (5) years has resulted at the end of that five (5) year period with ten (10) centres and two hundred (200) placements.

The AEIOU Foundation has a historical track record in the provision and delivery of service. In order to begin the first centre recurrent funding of one million dollars (\$1M) per annum is required to fund an initial forty (40) placements. An annual review of the project is required and then negotiations will proceed for further funding for the remaining placements on completion of the initial project.

¹³ Personal Communication with Bob Buckley from Aspergers Autism Advocacy Association (A4) and Dr John Wray (Paediatrician) 2011

¹⁴ Personal Communication with Dr James Morton (AEIOU)

Potential Issues

There are several potential issues which are peculiar to South Australia and directly relate to the development of an initial hub facility. Aside from the Federal political landscape, there are variables within State Government Legislation, Occupational Health and Safety (OHS) regulations, Taxation laws, Quality Assurance indicators and a plethora of complexities related to the highly regulated nature within the children services sector.

Expectations within the wider disability community is that we will see a lot of stalling around the NDIS. The disability sector recognises that this is at least five (5) years away. During that time State Governments still have a responsibility to match the Federal Government funding as per the CDSA.

The AEIOU model has already been presented by the writer to the newly appointed South Australian Premier The Hon Jay Weatherill and his staff at a meeting on 17th February 2011, when the Premier held the Education and Early Childhood Services portfolio. In 2006, the Hon Jay Weatherill in his capacity of Minister for Disability demonstrated a unique understanding of the entire disability sector. These two (2) previous portfolios have been a perfect political platform for the Premier. The writer thus identifies that this is a significant and an opportune time for the Weatherill government to take ownership of this proposal and announce an ongoing commitment to recurrent funding of AEIOU services prior to the next State Election in South Australia.

The writer also wishes to acknowledge that the Inclusion Support Subsidy (ISS) of sixteen dollars and thirty cents (\$16.30) per hour which the Commonwealth Federal Government currently provides to child care centres, is not made available to AEIOU centres. That subsidy is for a Disability Support worker and is made available for a child with ASD to attend an accredited child care facility. Access to that Commonwealth funding would improve service delivery to children with ASD who attend facilities overseen by the AEIOU Foundation.

Primary and Secondary Education

The writer has consulted with numerous families of children with ASD regarding the many limitations and shortfalls in the education system. Students presenting with ASD and significant levels of learning difficulties require different education provisions to those with average or above academic abilities¹⁵.

¹⁵ Synergies Economic Consulting; Economic Costs of Autistic Spectrum Disorders, 2010

However the families of children with ASD seeking suitable primary and secondary education programs for their children are limited in their choices. As a result, many families are resigned to the fact that if a suitable educational placement is found, usually it is located in a metropolitan area far removed from their own living arrangements. Furthermore families living in remote rural areas are substantially disadvantaged by their limit in choices.

The writer suggests that there are currently only four (4) types of 'choices' available for families when making a decision on the educational futures of their children with ASD. Each of these choices fall below the bar of an acceptable response to the educational needs of children with ASD; mainstream schools arguably being at the top of the list. These options are listed as follows:

1. Mainstream Schooling with School Support Officer (SSO)
2. Special Class within Mainstream School
3. Special Needs Schools
4. Home Schooling

Mainstream Schooling with SSO

Mainstream schooling is generally an option for students with very mild levels of ASD or for students positioned on the high functioning end of the spectrum, who are diagnosed with Asperger Syndrome. There is a significant lack of support for children in terms of funding in primary and secondary schools with respect to School Service Officers (SSO's). Currently some schools have no funding for students with ASD in the mainstream sector and as a result families have no other option other than seek opportunities outside of their immediate community. Once a suitable school is identified, most families are still unable to access enough funding for support of their children with ASD.

The Department of Education (DECS) has initiated a program that contracts a teacher to act as a Disability Co-ordinator in mainstream schools in various strategic locations. The writer suggests that the Government implements a strategy that provides some of these Disability Co-ordinators with a myriad of resources that further equip these educators with a high level of theoretical and practical skills, to effectively deal with children who have ASD.

It is highly likely that students with ASD will be subjected to years of isolation and abuse within the mainstream schools. It is well documented that students subjected to bullying develop severe mental health issues and as a result they are likely to self-harm, engage in challenging behaviours

and project their anger onto others¹⁶. It is imperative that the Government of the day also equips children with ASD with a variety of strategies to deal with bullying in mainstream schools.

Despite previous attempts by all governments to implement effective strategies to prevent bullying, they are inadequate. The writer strongly recommends that governments reassess their strategies and fund a task force to assess current strategies and remedies to prevent bullying within the school yard.¹⁷ Strategies to control and minimise bullying should be enforced at mainstream schools and a review of these strategies should occur on an annual basis. Any school should be held responsible for a child who is bullied and especially where appropriate measures are not undertaken by the school. In the event that bullying strategies are inadequate or not enforced, appropriate levels of funding and resources, based on the individual's needs, should be provided to families to home school a child with a disability. Please refer to page 18 of the submission for further discussion on home schooling options.

Special Class within a Mainstream School

Special classes within a Mainstream School are an option for students with ASD who have more moderate to severe levels of challenging behaviours. The writer has identified two (2) examples of schools that demonstrate excellent support policies for children with ASD. The St Mary's unit within an Independent School, Cabra College in South Australia is a prime example of a school that embraces children in a Special Unit with a policy of support and embracement from their mainstream students. In the qualitative opinion of the writer the "buddy" system works effectively and efficiently within this school.

Another example of this model personally sighted by the writer occurs in a Government School namely the Upper Coomera School located in between Brisbane and the Gold Coast Queensland. Like Cabra College in South Australia, a suitable funding model supports this school and successfully embraces children with ASD.

Special Needs Schools

Students with moderate to severe levels of ASD presenting with an Intellectual Disability and "Higher Needs" require greater levels of support. Many "experts" or "intellects" within the disability sector simply regard these Special Schools as antiquated. The writer disagrees and suggests that some of

¹⁶ Asperger Syndrome and Bullying Strategies and Solutions; Nick Dubin *Jessica Kingsley Publishers* 2007

¹⁷ Challenging Behaviours and Bullying Strategies

<http://www.autism.org.uk/living-with-autism/understanding-behaviour/challenging-behaviour/self-injurious-behaviour.aspx>

these schools offer a greater level of support and therapies for children with disabilities. (Please refer to Appendix A for examples of Special Needs Schools for children with varying type of disabilities)¹⁸.

For a special school to be effective it requires a student to staff ratio of at least two to one (2:1) and access to specialised services such as speech and occupational therapy within the educational setting. Other internal and external educational programs such as art, music, gym, horse riding, swimming, and so on are aimed at developing relationships in and outside school communities. Gaining independence for students with ASD is the major aim of these educational facilities.

In the main Government funding into these educational facilities are inadequate and currently have no specialist therapies and a poor student to teacher ratio of eight to one (8:1). Generally underfunded government schools then require an injection of “one-off” capital expense to upgrade the educational facilities with more secure premises to maintain the safety of the students with ASD. The writer in no way belittles the qualifications of the staff within these educational facilities. Rather he stipulates that the levels of staff are inadequate due to a lack of recurrent funding.

Reference is now made to an existing model of Best Practice which enables the community to embrace children with ASD. Optimum levels of support in terms of staff, specialist services and programs of socialisation and independence currently exist in South Australia. The writer refers to the St Patricks Special School located in Dulwich, South Australia, which is an example of a multi-disciplinary model for all Governments to adopt so that all children with ASD can be afforded the same levels of expertise in education. Students of this school are funded by a combination of Federal, State, Catholic, private fees and fundraising from the parents and friends of the school community. The total annual cost of collective funding is approximately eighty thousand dollars (\$52K) per student¹⁹. (Please note again that this amount is subsidised mostly by the Catholic Education System and is in far excess of the funding allocated by the Federal Government).

Home Schooling

As mentioned previously numerous students with ASD are home schooled due to a severe lack of support within the mainstream educational system. As described before many children are isolated at school labouring with no friends and subjected to high levels of bullying. These children eventually cannot access alternative suitable education and families are left with NO choice other than home school their own children with ASD.

¹⁸ Appendix A – Education Options for children with ASD: Ministerial Advisory Committee, 2010

¹⁹ Personal Communication with Craig Battams (Principal of St Patricks Special School) 2011

Current packages to home school children with ASD are poorly resourced and underfunded. Usually parents resign from their day to day occupational working duties and provide the education for their children with ASD. Again this reduces the economic productivity of the family unit, placing further strain by an increase in the stress levels of parent carers. The writer states that this is unacceptable and funding to compensate these families is commensurate with other forms of education funding as recommended within this submission.

ASD Specific Centres

The writer strongly supports the announcement by the State government as described in a media release from the Education Minister of the day, the Hon Jay Weatherill²⁰ to establish ASD Specific Centres²¹ for primary and secondary learning students based on the Hub and Spoke Model²².

Students with ASD who are prevented from learning to their full potential due to lack of choices should have access to five (5) ASD learning centres. These centres need a central City location as well as in the Northern, Eastern, Southern and Western metropolitan areas. The City or “Hub” Facility will provide resources to families and programs to children with ASD including those in rural and remote areas via internet. The “Spoke” Facilities located in the metropolitan areas will be located in existing mainstream schools. The writer notes that these specific ASD centres have not come to fruition.

The ASD centres will be resource management centres, not only for children with ASD but also parents, carers and advocates of children with ASD. For families seeking specialist services, the centres will offer access to occupational therapy, speech pathology, hydrotherapy and other specialist services. The centres will also provide resources for the all staff within primary and secondary schools that are involved with the education of children with ASD in the mainstream sector.

EMPLOYMENT

Article 27 of the United Nations Convention of Rights of People with Disabilities clearly states that Governments must;

“recognise the right of persons with disabilities to work on an equal basis with others”

²⁰ Media release from the Minister of Education, the Hon Jay Weatherill, December 2010
<http://www.adelaidenow.com.au/news/south-australia/m-special-schools-revamp/story-e6frea83-1225964766222> -

²¹ Appendix B – Education Options for Children with ASD: Ministerial Advisory Committee 2010

²² Appendix C – Education Options for Children with ASD: Ministerial Advisory Committee, 2010

and this right includes;

“the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible ... [and] including those who acquire a disability during the course of employment.”

Adults with ASD must be protected from discrimination in accessing work and employment in all areas including the recruitment, hiring, continuance of employment, career advancement and safe and healthy working environments which must provide protection from harassment, bullying and exploitation. They must have equal work opportunities and equal pay for work of equal value, as well as access to all avenues for the redress of grievances as are available to all other workers including trade union rights and all labour laws. It is essential that appropriate remuneration is afforded to people with the required skills of that occupation.

It follows that organisations must enhance the workforce capacity for people with ASD and they must provide ongoing training and internal programs to provide sustainability within the workplace.

Technical and vocational guidance, continuing vocational training, support through adequate and appropriate placement services, work experience through the open labour market and ‘on-the-job’ support and training must be available for all workers with ASD. Employment opportunities must be available in sheltered and open employment, in the private sector, in the public services and for self-employment, entrepreneurship, the development of cooperatives and other innovative work arrangements. As a result Governments should provide additional opportunities for employment of people with ASD by the provision of additional policies including affirmative action programs, incentives for employers and any other appropriate measures.

For people whose employment skills are limited, it is essential that effective day option programs are provided which maximise the participation of people with ASD. These programs must be meaningful, purposeful, physical and stimulating taking into account the many sensory issues that are specific to people with ASD. One example of a suitable specific ASD program known to the writer is run by “Excellent Day Options” located in Campbelltown.

Bedford Park Industries is a well recognised service provider of accommodation, supported accommodation, day option programs and employment opportunities in South Australia. It is a leading example of a private, professional and entrepreneurial enterprise applauded by the wider community. It is funded by the combination of government money and the reinvestment of generated profits after payment of employees with ASD. As a result, Bedford Park Industries is a not-

for-profit organisation offering a diverse range of employment opportunities for people with ASD and consistently shows an increase in revenue, profit and growth.

LONG TERM ACCOMODATION

Article 19 of The United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, recognises

“the equal right of all persons with disabilities to live in the community, with choices equal to others, and ... their full inclusion and participation in the community”

There is no one type of accommodation model which will suit the needs and wishes of all people with ASD. The right to choose the type of residence and where and with whom they will live, in the same way as all other members of our community, is paramount. Therefore, no person with ASD must be forced to live in a particular type or form of accommodation or with a particular group of people unless they, or their families or advocates who speak for them, have chosen and agreed that this accommodation best meets the person’s needs.

Furthermore Article 28 of The United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, recognises:

‘the right of persons with disabilities to an adequate standard of living for themselves and their families.’

It is impossible to discuss accommodation options available to people with ASD, without considering the support that may be required, to maintain and improve the person’s quality of life.

Whatever the type or form of accommodation which a person with ASD may choose, a full range of necessary supports, including personal and in-home supports as well as community supports, must be provided to ensure that the person with ASD can be involved and included by optimising participation, and in no way segregated or isolated, from their community. These levels of support will vary. For some this may be minimal (eg help with shopping once a week) but for those with more severe levels of ASD, that support may be required up to twenty-four (24) hours per day and seven (7) days per week.

All community facilities and services available to members of the general community must be made available, on equal terms and conditions. These facilities and services should always be responsive to the needs of people with ASD. Placing people with ASD into community accommodation is

geographically easy but socially very difficult. If the appropriate level of support is not available, we have not improved a person's quality of life, and in fact may have simply made them even more segregated and isolated from their community. Therefore irrespective of the type or form of supported accommodation in which a person with ASD is living that support must ensure the overall person's physical, mental and emotional health and 'well-being'.

The government, regardless of political alignment or agenda, should provide administrative and financial support to individuals, families and organisations to build as wide a range of appropriate accommodation as is possible for people with ASD. Individuals, families or groups of concerned people should be encouraged to build accommodation which is designed to meet the specific needs of an individual with ASD. The building of accommodation based on Universal Design Principles should be encouraged.

The government, regardless of political alignment or agenda, must ensure sufficient funding and resources are available to provide adequate levels of training, wages and career opportunities to those people working in the provision of disability support. As cited previously on page 4 of this submission, the writer supports the National Disability Insurance Scheme (NDIS) and Self Managed Funding (SMF)²³ approaches for the provision of funding to disability services.

The people and workers providing this support must be aware of the specific needs of the individuals they support. Support workers and service providers should be trained in all appropriate modes, means and formats of disability service provision and especially in an awareness and understanding of the issues and values surrounding disability.

All support services provided to people with ASD in all aspects of their life must be regularly and effectively monitored by independent authorities. Reports, by any person or organisation, of poor and inadequate support provision or abuse or exploitation of a person with a disability should be investigated, reported and, where appropriate, prosecuted. For further information on Abuse and Exploitation refer to page 23 of this submission.

TRANSPORT

Article 20 of the United Nations Convention of Rights of People with Disabilities clearly states that Governments must take;

²³ Self managed funding is currently offered by the Government within a pilot program to some consumers who satisfy certain criteria and then ultimately manage their own disability service support packages

“effective measures to ensure personal mobility with the greatest possible independence for people with disabilities.”

People with ASD have minimal physical incapacities but can still be effectively imprisoned in their own homes due to their high levels of sensory and anxiety issues. This may cause major difficulties in addressing the person’s health and other needs by restricting timely access to services. Accessible and reliable transport services must be made available to all people with ASD.

These transport services must include public transport (buses, trains and trams), taxis, access cabs, school buses and private vehicles. The number of these vehicles, especially access cabs, must be adequate to meet the needs of all people with ASD requiring transport especially at night and at other special occasions (e.g. Christmas/Easter etc).

Transport safety standards for all forms of transport must be met (e.g. safety belts and video monitoring in school buses). The access taxi service, due to insufficient numbers of access cabs available, also fails to meet those needs. As the Productivity Commission’s Report July 2011 states, it is essential that people with ASD are able to attend community venues and to contribute to one’s workplace greatly improves productivity and that person’s quality of life.

Subsidy systems for the cost of transport services must explore all possible new technologies (eg Smartcard)²⁴. The current voucher system for the partial payment of fares and for only a limited number of trips is totally inadequate. The Federal Government should consider making the cost of transport subsidies a responsibility under the Commonwealth State and Territory Disability Agreement (CSTDA) or the National Disability Insurance Scheme (NDIS).

Currently, public transport and taxi services are state government responsibilities. State governments are aware of the need to expand and improve these services to meet the demand. They are also aware that an increase in the subsidies paid to people with ASD would greatly assist people with ASD to be more mobile. The financial responsibilities should remain with the states to provide funds for transport services.

FREEDOM FROM ABUSE AND EXPLOITATION

Article 16 of The United Nations Convention on the Rights of Persons with Disabilities, to which Australia is a signatory, states that;

²⁴ Smartcard is an alternative system for persons with ASD to access greater services
http://www.trisias.org/research/guidelines/cards_and_smart_media.htm

‘Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with all others.’

As such, “disability rights” are in fact “human rights”, which people with disabilities should be able to experience and enjoy to their fullest extent.

However, it must be acknowledged and understood that people with ASD, women and children in particular, are many times more likely than average to be subject to some form of abuse in their lifetime. Potential abuse of children and adults with disabilities and in particular people with ASD is eight (8) times more likely than that of a person without ASD²⁵.

Government, regardless of political alignment or agenda, must take every possible measure (legislative, judicial, administrative and social measures, including educational and training measures) to protect all people with ASD, both within and outside of their home, from all forms of abuse, violence and exploitation. All people with ASD, their families, those who advocate on their behalf and those who provide support must be made aware of those legislative, judicial and administrative and other measures by the provision of clear information and education on how to avoid, recognise and report instances, and where appropriate, suspected instances of, abuse or exploitation.

Monitoring authorities must ensure that all instances of abuse or exploitation against people with ASD, by any person or organisation, are identified, investigated, reported and, where appropriate, prosecuted. In cases of proven abuse or exploitation, legislation must provide adequate and appropriate penalties and correctional procedures to ensure that the abuse or exploitation ceases and is prevented from re-occurring. Governments shall provide adequate physical, psychological and emotional support to the abused or exploited person with ASD to ensure their rehabilitation and to reintegrate them into their community at the pace and in the manner of their choosing.

Recent events in South Australia has led to the alleged sexual abuse of a number of children with intellectual disabilities including that of children with ASD on a state funded school bus. As stated previously on page 22, transport safety standards for all forms of transport must be met (eg safety belts and video monitoring in school buses). Dignity for Disability MLC, the Hon Kelly Vincent is currently reviewing disability legislation and police prosecution procedural processes so that credible evidence is presented in courts so that perpetrators of sexual crimes on vulnerable children/people with ASD is eliminated.

²⁵ Personal Communication with Sam Paior (Disability Advocate and former d4d Board Member), 2011

Complaints System

A complaints system and the appointment of an independent person to act as a 'Complaints Officer' as part of ASD Provision Services is recommended and the need for this position to be seen as completely independent from any other association. Currently Dignity for Disability (d4d) MLC, the Hon Kelly Vincent has introduced a Bill to parliament that amends the existing outdated 1992 SA Disability Legislation. One of the main amendments to the Bill is the provision of a Disability Commissioner or Ombudsman who can exercise immediate powers in the event that a report of abuse is made to a 'Complaints Officer'.

The writer also recommends that the government provides immediate funding to Autism SA immediately to appoint an "Autism Complaints Officer", that directly reports to the Disability Commissioner.

The complaints process must be very simple, easily accessible and transparent. Many people with ASD and their carers, after years of unfair treatment, are reluctant to complain about an issue they clearly see as an error or oversight because of the fear that a complaint will simply make their situation worse, resulting in existing funding being withdrawn. For many others, years of failure to receive even a basic hearing of the issue have left them and their families feeling that to complain would be 'simply a waste of time'.

There must also be a mechanism in place to ensure a rapid and efficient resolution of complaints. Unlike many other government promoted schemes, Autism SA must develop a reputation for dealing with complaints fairly and expeditiously. Failure to do so can only increase community scepticism and further harm the reputation of the ASD sector.

Advocacy rights and services must be preserved and strengthened. The writer suggests that any appointment of an independent body to represent people with ASD include the right, or even a requirement for, Case-managers, service providers and/or support workers to report issues on behalf of the people they support which they feel are unfair or of concern. Abuse by families, service providers or support staff, in its many forms, has always been a major issue across the sector and especially for those people with more severe autistic tendencies and intellectual disabilities.

Mandatory reporting of all forms of abuse of people with ASD of all ages should be a feasible option and over time, should become enshrined in South Australian Disability Legislation. At the least, there is a professional obligation of trained workers associated with people with ASD to report abuse of

any form. Current opinion is that abuse and inadequate support afforded to people with ASD, may be a major cause of ‘challenging behaviours’²⁶.

MENTAL HEALTH

On-going mental health illnesses are simply another form of disability. It is becoming clear that many people with ASD, as they age, are at a high risk of developing a range of mental health problems which may significantly impact on their on-going support needs. That is, people with ASD present with a dual disability²⁷ and the co-morbidity of that mental illness is very high in people with ASD²⁸. Long-term mental health issues (eg schizophrenia, bipolar disorder, depression, Obsessive Compulsive Disorders, otherwise known as OCD) commonly present in individuals with ASD.

The inadequate assessment processes and support of people with ASD and mental health issues, is of great concern. This may require governments to develop assessment tools and procedures to identify these individuals and appropriately change their support packages to meet their new needs. For many years, governments have saved money by simply moving these people back and forth between the Mental Health Services and Disability Services. Unfortunately, most of these people ‘slip through the cracks’ and receive little or no support at all. It is essential for many people with ASD who have long-term mental health issues, to be eligible to access the same range of support options as people with other forms of disability.

As with people without ASD, mental health illnesses may often be episodic in people with ASD and mental illness will be interrupted by long periods of ability to cope with and live effectively in normal community situations. For those people with episodic mental illnesses, a broadening of the current Medicare system to include a wider range funding options for mental health treatments and supports may be a better alternative.

People with ASD and with long-term, on-going and permanent mental health problems should be able to apply for assessment of specific settings by Autism SA, and if found eligible, to receive the same type of support package as any other person with a mental health disability.

²⁶ Challenging Behaviour Exploring Bullying with Adults with Autism and Asperger Syndrome; A Photocopiable Workbook - Anna Tickle and Bettina Stott *Jessica Kinsley Publishers 2010*

²⁷ Journal of American Academy of Child and Adolescent Psychiatry. 2008 Aug; 47 (8):921-9

²⁸ Co-morbidity is reported to be prevalent in people with ASD – Mental Health Assoc, 2010

HEALTH

Article 25 of the United Nations Convention of Rights of People with Disabilities clearly states that;

“Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”

and that governments should

“prevent discriminatory denial of health care or health services or food or fluids on the basis of disability”.

It is a fundamental human right for all people to be provided with easy access to age and culture appropriate information and support regarding their health, both physical and mental. The health sector must be committed to breaking down the barriers which can often prevent people with ASD from accessing such information or receiving appropriate medical support. All people with ASD must have access to the same range and quality of health services as all other members of the community. Those health services that are needed for the treatment of specific disabilities (eg early interventions, surgical procedures, services designed to minimise the effects of ASD such as Occupational Therapy and Speech Therapy) should be provided to all people with ASD when appropriate and irrespective of their ages, either young or old.

No aspects or types of health care or public health programs including sexual and reproductive health programs should be denied or restricted to any persons including people with ASD. In fact sexual education should be encouraged to help facilitate loving and wholesome relationships between people with ASD as well as people with ASD and people without ASD.

All health care must be provided to people with ASD at the same standard of free or affordable rates as charged to all other members of the community. All health services must be as easily accessible as possible and should be provided in a timely fashion and as close as possible to the person’s own community including in rural areas. This is particularly important for the frail aged and people with ASD.

All professionals and practitioners working at all levels of medicine, nursing and other allied health services must receive appropriate training to raise their awareness of the human rights, dignity, autonomy and needs of people with ASD and other disadvantaged groups in our community.

Appropriate training must also be required of all staff working in the health care industry including receptionists, administrative officers and management at all levels. All professionals and practitioners working at all levels of medicine, nursing and other allied health services must practice

the highest ethical standards in their work with all people, and particularly with people with ASD , in both public and private health care services.

People with ASD must be protected from discrimination in accessing health insurance and life insurance programs and policies where these are available to all other members of the community.

Formal procedures and protocols, which allow all people, and particularly those with ASD or their advocates, to report breaches of the standards of quality and ethical health care services, must be in place. All such reports and complaints must be quickly investigated and appropriate action taken.

This action may include the prosecution of the health practitioner for serious breaches of these standards.

All opportunities, which can assist the continued improvement in the delivery of health services to all members of our community, should be pursued.

AGED CARE

As for people without ASD, the needs and wants of people with ASD escalate with age. It is essential that there is a need for specialised aged care settings for people with ASD.

Many people with ASD are denied the opportunity or the capabilities to raise their own family. It follows that people with ASD will age without the necessary support networks offered by their children and other relatives. In fact the most likely scenario is that a brother or sister may be the only remaining support for a person with ASD as they approach old age.

Federal Governments should provide specialised aged care facilities that adequately accommodate people with ASD and the high degree of necessary support networks.

SUMMARY

This submission covers the various aspects and shortfalls in service delivery of a person with ASD in South Australia highlighted by the United Nations Convention of Rights of People with Disabilities.

Early diagnosis, early intervention, a range of appropriate choices in primary and secondary schooling and tertiary education are essential. Long term accommodation options, attention to mental health needs, employment opportunities including appropriate workplace and Day options

are highlighted. Health and Aged Care for people with ASD are high on the disability agenda too. It is acknowledged that we, as a population in Australia, are living longer and this also extends to people with ASD.

There is overwhelming evidence tabled within the Productivity Commission's Report on the recommendation of an NDIS to suggest that an economic investment in Disability (including that of ASD), will increase the total productivity of the nation. That opinion and the enormous benefits of early intervention are supported within the reports from Synergy economics consulting where investment in children with ASD has profound economic benefits for our community and families and for Australia.

It is the writer's opinion that the specific recommendations from within this submission will have a positive impact in the economy of South Australia and improve the lives of people with ASD, their families, advocates and friends.

References

1. Dignity for Disability Policy Platform
<http://www.d4d.org.au/Policies>
2. Synergies Economics
Economic costs of Autism Spectrum Disorder
April 2010
3. Education options for Children and children with Autism Spectrum Disorder
Ministerial Advisory Committee Students with disabilities
October 2010
4. The AEIOU Foundation
www.aeiou.org.au
5. The Productivity Commission Report on Disability services and the Implementation of the NDIS, July 2011

Appendix A

Most of the Special Schools in South Australia cater for children and students with a primary diagnosis of intellectual disability but there are three schools specifically for children and students with other disability types. Regency Park School caters for children and students with physical disabilities and communication needs, the South Australian School for Vision Impaired (SASVI), caters for children and students with vision impairment and Kilparrin Teaching and Assessment School and Services caters for children and students who are deaf blind or have complex sensory impairments and additional disabilities. Regency Park School and SASVI offer a hub and spoke model of service. Both schools have a main campus and satellite programs located in mainstream schools (i.e. the *Link Program* and *Vision Support Program*, respectively). They also offer state-wide support services. Kilparrin Teaching and Assessment School and Services have a main campus and offers state-wide support services, but does not have satellite classes.

The hub and spoke model of service provided by Regency Park and SASVI is similar to the way autism specific education is provided in New South Wales by ASPECT and in Victoria by the Department of Education and Early Childhood Development. The model allows for disability specific environmental conditions in specific purpose settings and for experts in disability specific education to work with the children and students enrolled. These experts are also available to offer their professional expertise to colleagues in mainstream services where children and students are included.

Anecdotally, the model appears to have been successful for children and students with physical disabilities and sensory disabilities in South Australia, and for children and students with ASD in New South Wales and Victoria.

Appendix B

The data showed that most children and students with ASD were located in schools in the northern metropolitan area, including the peri-urban communities around Gawler and the Barossa Valley. Other areas to note were Marion and Christies Beach in the southern metropolitan area. In the country Kadina, Wallaroo, Murray Bridge and Mt Gambier had higher numbers of children and students with ASD. It was noted that special schools and disability units were available in these areas, which raised the question of the correlation between the availability of specialised services and where children and students with ASD attended school.

From Autism SA's perspective, the total number of children and students with ASD attending special schools was 456 (13 per cent of the total database). Overall, special schools had the highest percentage enrolment of children and students with ASD with an average of 40 per cent enrolments (ranging from 0 to 94 per cent)⁵. The majority of these children and students had a diagnosis of Autistic disorder. Only ten children and students with Asperger's disorder were enrolled in special schools.

Modbury Special School had the highest *number* of children and students with Autistic disorder (n=81; 53 per cent of their total enrolments) and Ashford Special School had the highest *percentage* of children and students with Autistic disorder (n=62; 94 per cent of their total enrolments). It may appear from these data that Modbury and Ashford special schools have become de facto special schools for children and students with Autistic disorder (because of their high proportion of students with this disorder). However, the Ministerial Advisory Committee: Students with Disabilities has no evidence that high numbers of children and students necessarily indicate specialist education for this cohort, as the components that indicate quality educational provisions may not all be in place i.e. staff training and ongoing support, curriculum adaptations, appropriate instructional environments, behaviour support strategies and family involvement. It was beyond the scope of this project to determine if these education settings are providing quality educational provisions for children and students with ASD. This is an area for possible further investigation.

Most of the children and students with ASD attending special schools were in the metropolitan area (n= 412; 90 per cent). Of the country special schools only Murray Bridge Special School had comparable enrolment (i.e. based on percentage) to the metropolitan special schools (n=15; 50 per

cent of their enrolment). All other country schools had 30 per cent or less enrolment of children and students with ASD.

The data also showed there were high numbers of children and students with ASD in schools where there were disability units (n=354; 10 per cent) and special classes (n=550; 16 per cent), but there were also high numbers of children and students with ASD included in mainstream classes (n=1930; 57 per cent). More children and students with Asperger's disorder (78 per cent) than Autistic disorder (40 per cent) were included in mainstream classes. Further, some schools with disability units or special classes also had low numbers of children and students with ASD.

Project group members were unable to determine clearly from the data if there was a correlation between the availability of specialised services and higher enrolments of children and students with ASD, although in some cases it would appear so. In particular, the lower number of children and students with Autistic disorder attending mainstream classes correlates with the higher incidence of intellectual disability associated with this diagnosis and the increased likelihood of these children and students accessing special education settings compared to those with Asperger's disorder. The data generally reflected the State's education policy of inclusion and the provision of a range of educational services from which families can choose, with a higher incidence of choice in metropolitan and outer metropolitan locations.

Autism SA consultant teachers further informed the project group that most children and students with ASD are distributed across a range of school settings and within schools across a range of classes. They reported that in mainstream settings there were a few cases where children and students with ASD were clustered together, either in a disability unit or class, or grouped together in a mainstream class because of the exceptional skills of the classroom teacher.

Appendix C

There is a range of educational options for children and students with ASD available in Australia, including autism specific settings (schools and units). Roberts and Prior (2006) briefly reported on specialist autism education provisions as part of their review of effective models of practice. They reported on services provided by Autism associations, Government, Catholic and Independent education sectors, and some children were recorded as home schooled.

Where specialist autism schools, units and classes operate, some appear to be successfully based on a hub and spoke model of service structure, where there are specialist settings (the hub) and satellite classes or units in mainstream settings (the spokes). This model provides opportunity for integration and inclusion with access to intervention from autism specialists as required, and with varying intensity. Victoria has six Government autism specific schools, some of which have satellite classes co-located with mainstream schools and in New South Wales, ASPECT operates autism specific schools with satellite classes hosted by mainstream schools. ASPECT's education services are non-government and have grown to provide six special schools with two more planned in the near future and 78 satellite classes in metropolitan and country regions of New South Wales. ASPECT's enrolment in 2010 was approximately 700 with an additional 700 children and students with ASD on their waiting list (Reference T Clark [ASPECT] 2010, pers comm June).

In addition to ASPECT schools, New South Wales has a number of Government autism specific special education classes, as well as other non-government autism specific education providers, such as Woodbury School, and Giant Steps School. Woodbury School is based on an Applied Behaviour Analysis approach to education for children and students with autism and Giant Steps is based on its own approach, which originated in Canada. The first Australian based Giant Steps school was opened in Tasmania in 1994.

Concerning other jurisdictions, Queensland also has autism specific schools and units. The Australian Capital Territory has autism specific units co-located with mainstream schools and in Western Australia there are four preschool and junior primary autism specific units for four and five year olds, which work towards the children's integration in mainstream schools. Western Australia's autism programs are offered to four and five year olds in ten Education Support Centres (which are similar to South Australia's Disability Support Units) and several of the ten special schools in Western Australia offer programs for children and students with ASD from kindergarten to year 13.